Poor Families in America's Health Care Crisis

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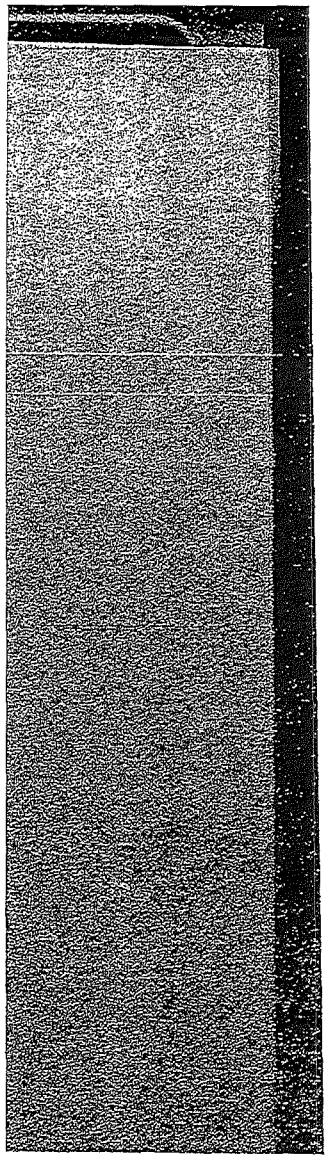

their work experience was characterized by unstable jobs and low wages.

We can usefully describe our sample of families as a "middle cut" of low-wage and unemployed families. The families we describe were certainly struggling. Most were barely making ends meet, they were cycling between jobs and unemployment, and most were often behind in paying their bills. As we shall see, they often experienced lapses in health insurance, they had problems with housing, and they had difficulty paying for food, utilities, and transportation. However, in most cases, mothers and children were still together, and many found periods of stability that punctuated the periods of crisis and ongoing chaos that permeated much of their lives.

Even this middle-cut group of families experienced pressures, tensions, and discontinuities that took them out of the research process for a time, often leaving us with an incomplete record of their experiences. As we noted earlier, our original plan called for interviewing families on at least a monthly basis for eighteen months. However, only a minority of the families were available on a regular basis over the entire eighteen-month period. Thus, there are often blanks in our record of the families' life experiences. Families that experienced a sudden eviction (a more common event in Texas than in the other states because of the lack of tenant protection regulations), a sudden critical medical crisis, or any of a number of other setbacks were often difficult to find and unavailable for participation in the research project for a period of time. However, it was important to the nature of this research to keep these families in our sample. If we had excluded all families for whom there were discontinuities and missing data, our conclusions would have been based on an atypically stable group of poor families.

We also found that family life was sufficiently complicated that, on occasion, families did not know the answers to questions that, at least during the planning phase of the project, had seemed straightforward. These included such questions as whether the respondent was employed. The women in our study, like those in other studies of marginal workers, experienced frequent periods of unemployment and job hunting. For days, or even weeks, they might have been under the impression that they had their next job lined up. In such situations, they may well have told the interviewer that they were employed, even though they had not yet worked or received their first paycheck. Health

insurance was also confusing. The complexity of the application and recertification process for Medicaid often led to misinformation concerning a family's status. We found, for example, that a mother might think that her child had Medicaid coverage because she had filled out the application and been told that she was eligible. However, when the child needed medical care, some mothers found out at the provider's office that the child's coverage had not been approved. Upon returning to the Medicaid office, many mothers found that their file was incomplete and missing a critical piece of documentation or that the application had simply not been processed yet.

Another complicated set of issues related to the amount of the family's welfare benefit. The amount of the welfare payment varied from month to month, often for unpredictable reasons. Unforeseen changes in family circumstances, a parent's inability to meet all the welfare requirements, and delays and errors at the welfare office, among other complications and problems, all contributed to variations in welfare payments. Mothers found it difficult to predict their welfare payments or to explain past payments. As a result of all of this complexity, almost every family's narrative includes holes. As we describe families, we will indicate where information is missing.

Because we were intimately involved in the San Antonio component of the ethnography, we draw heavily from those interviews, although we use survey and ethnographic data from the other sites as well. Our focus on San Antonio is also motivated by the fact that Texas has the highest number of uninsured children and adults in the nation and the fact that it serves as an example of the dilemma that arises from the combination of an employment-based health insurance system, a shift in employment toward service-sector jobs that do not provide benefits, and the inability or unwillingness of legislatures to raise taxes.

Although many of the differences among families we document can be traced to different state and local policies, in the ethnography some of the differences among cities probably reflect variations in the way families were recruited. In San Antonio, most families were recruited through public housing programs and multiservice community organizations. In Chicago, families were more likely to be recruited through Head Start programs. In Boston, they were more likely to be recruited through child care centers. In all cases, these families were in contact with public agencies, and in the case of Chicago they were connected

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with a service, Head Start, which serves only a minority of eligible families. It is therefore clear that these families were all savvy enough and energetic enough to connect with service agencies. Various state characteristics also influenced the research process itself. San Antonio families presented the greatest challenges to the research project because of their high rate of residential mobility. The San Antonio families experienced more evictions and other changes in their housing situations than did families in the two other cities. This was related, at least in part, to the speed with which landlords can evict tenants in Texas. In Massachusetts, and to some extent in Illinois, tenants enjoy greater protection from eviction.

Although the families we studied were not those that were most down-and-out, and although they were attached to helping agencies, they all experienced the unpredictable instabilities of life at the economic margin. Families in Boston were doing marginally better than families in Illinois or Texas. Again, this to some extent reflects the fact that they were recruited through child care centers, they lived in a state with high welfare benefits, and that there were a variety of local health services available to them. As the data we present later reveal, parents in families that used child care centers were more likely to be engaged in somewhat stable employment. In the end, however, the variations among the three cities were of relatively small scale compared with the major impacts of poverty and instability.

Understanding Instability: The Need for Qualitative Research

Although our core focus consists of the nature and consequences of the fragmented and incomplete health care financing system upon which low-income families depend, very early in the study we realized that problems related to health pervaded the lives of the families we studied as well as the narratives they provided. It was immediately obvious that the means-tested nature of the health care and other support systems that they relied upon, and the fact that the requirements of those organizations were often seriously incompatible with work and the ability to establish family routines, meant that these families lived with constant uncertainty and instability. They could take very little for granted from month to month or even week to week. Their incomes varied widely, they remained on waiting lists for subsidized housing for

years while they lived in demoralizing conditions, their access to adequate nutrition was often tenuous, and their health care coverage was uncertain. Such instability can undermine the most sincere efforts to achieve self-sufficiency of even the most functional family and the most psychologically resilient parents. The theme of instability is therefore necessarily central to our story, and in order to illustrate how instability pervades the lives of low-income families, we must show how instability in health care is related to and exacerbates instability in all other areas of the lives of low-income families. Our task is to make some sense of the instability of the lives we recount and to relate that instability to the institutional and social structures that seriously limit the opportunities for social advancement of families that find themselves at the economic margin.

Alice O'Connor (O'Connor 2001) points out that today researchers who study poverty are in much the same situation as their progressive-era predecessors of over a century earlier. They face the challenge of shifting the focus of research away from a concern with the characteristics and behaviors of poor individuals and families and onto the nature of the economic system that seems to make poverty inevitable. As O'Connor and others point out, since the 1960s the study of poverty has become extremely sophisticated. Methodological innovations based on major data-collection efforts, including income maintenance experiments, large-scale social surveys, and advanced statistical modeling techniques have provided very useful insights that have put simplistic explanations of the causes of poverty to rest. A long tradition of quantitative work focuses on issues related to employment, income, program participation, and other characteristics of individuals and families that move on or off the cash assistance rolls (Braumer and Loprest 1999; Isaacs and Lyon 2000; Moffitt 1992; Moffitt and Winder 2003a; Moffitt and Winder 2003b). It is clear by now that the rise in single motherhood, the decay of our inner cities, and poverty are part of a complex set of social changes that are global in nature. Only the most intransigent ideologue would still contend that welfare is the sole and direct cause of single motherhood or the decline of the family.

For the most part, research on poverty has been quantitative, with the occasional addition of a qualitative component, and most of the policy debate has been informed by quantitative studies. The power of quantification and the scientific legitimacy that it conveys in discussions

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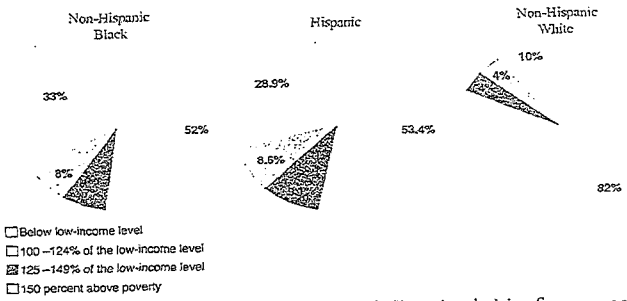

FIGURE 1.1. U.S. child poverty by race and Hispanic ethnicity. Source: 2003 Current Population Survey (March), U.S. Bureau of the Census.

the overwhelming size of the non-Hispanic population, the majority of the poor are non-Hispanic whites. Nonetheless, the fact that a disproportionate fraction of the poor are African American and Hispanic has had important implications for the evolution of U.S. welfare policy (Quadagno 1988a; Quadagno 1988b; Quadagno 1994; Weir, Orloff, and Skocpol 1988).

There can be little doubt that welfare policy and our public attitudes toward the poor have been influenced by our history of racial conflict and discrimination (Bonilla-Silva 2003; Gilens 1999; Lieberman 1998; Quadagno 1994; Weir, Orloff, and Skocpol 1988). Media coverage of the most negative and unappealing aspects of welfare and poverty have focused disproportionately on minority Americans and public support for antipoverty programs has been declining since they became associated with African American and inner-city poverty (Gilens 1999; Heclo 1995; Heclo 2001). The issue of race has always been divisive, and even many liberals wish that the topic could be laid to rest (Bonilla-Silva 2003; Schlesinger 1992). Clearly, many of the problems of African Americans and Hispanics result from education, employment, and language problems that leave them outside the economic mainstream (Wilson 1978; Wilson 1987). Yet their unique vulnerabilities reflect the continuing structural disadvantages certain groups face, related in part to subtle forms of institutionalized racism rather than overt bigotry (Bonilla-Silva 2003). It is impossible to discuss the

situation of poor families without dealing with the issue of race and ethnicity. Our survey sample, like our ethnographic sample, was primarily African American and Hispanic, a fact that reflects our sample design but even more so the fact that poor urban neighborhoods are disproportionately minority.

The new age-based shift in the burden of poverty from the elderly to families with children takes on a distinctly racial and ethnic dimension because a disproportionate number of poor families are African American and Hispanic. As we document in the following chapters, race and ethnicity, although often left out of the discussion, pervade one's experiences, and they affect where families live and work and, consequently, whether they have health insurance and if and where they get health care. Today the vast majority of poor children qualify for Medicaid or SCHIP, yet many do not enroll even though they qualify (Dubay, Haley, and Kenney 2002; Guyer 2000; Perry et al. 2000). This fact reflects many complex factors related to poverty and the bureaucratic complexity involved in the application and recertification procedures. Many of these factors are related to the social and political barriers associated with being African American or Hispanic. Discussing race and ethnicity as if they were separate from and independent of socioeconomic and other barriers to economic success and continuous health care misrepresents reality. In the United States today, minority-group status, especially for African Americans and certain Hispanics, places one at high risk of poverty and its negative consequences, including a lack of health insurance and difficulty accessing health care.

We Are Mexicans

To be "Mexican" in San Antonio is to live in a city replete with the symbols of one's culture of origin. Non-Hispanics have adopted Mexican dress and food and the beauty and ease with which they fit the geography and culture of the Southwest. To grow up a Mexican in San Antonio or any other American city, however, means that even as one participates in the economic life of the larger society, one remains conscious of one's difference. This fact is rarely articulated in everyday interactions or even in our ethnographic interviews. Ethnicity seems too basic an aspect of identity to require, or even lend itself to, verbal expression. Overt ethnic consciousness largely remains confined to the

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realm of political discourse, often of a confrontational nature. Yet the events of our families' daily lives were conditioned to one degree or another by the fact that they were "Mexican" and therefore, depending on their social class, education, skin color, dress, and more, different from the "Anglo," a term that refers to the large heterogeneous group of non-Mexicans whose defining characteristic is that they are the group with the greatest economic and political power.

In the Southwest, the Mexican and Anglo cultures have over the years evolved a degree of mutually beneficial rapprochement such that intermarriage between members of these groups presents fewer serious social difficulties than an interracial marriage. Even in the absence of an articulated consciousness of their Mexican ethnicity, however, for those with few resources, the fact of belonging to this specific group pervades everything they do. In Chicago, in which the large Mexican arrival is much more recent, the cultural distance is probably even greater. For our families with little money or social standing, it was difficult not to be conscious of the differences between themselves and others in social interactions, even when those differences went unspoken. As we learned from our interviews, in interactions with authorities and institutions, the families we spoke with could not help but be conscious of the fact that most of the clients with whom they shared the waiting room were Mexican or black. The fact that the caseworker might be a minority-group member as well did not alter this reality, nor did it alter their position in relation to the authority he or she represented. The system as a whole is defined by the Anglo, to whom they must continuously appeal for the necessities of life, often sacrificing elements of their basic dignity in the process. This degradation is a theme to which they return frequently in our discussions.

The Need for a New Discourse on Poverty and Health Care

Our fundamental argument is that academic researchers and public policymakers have not focused sufficiently on the impact of instability and the lack of routines on all aspects of poor families' lives or on the role of poor health and the lack of health care coverage in exacerbating that instability. Ultimately, we see no solution to this major social problem and personal tragedy other than a fully funded, federally

mandated, universal system of basic health care coverage. As we argue in Chapter 8, piecemeal and partial reforms may be an inevitable first step, but a continuation of the current system that focuses on work solutions and coercive welfare policies will never address the health care coverage problems of the poor.

The nation's experience with welfare since the 1960s has shown that the problems of poverty cannot be overcome by simple policies and programs, and it is unlikely that in the future policies based on coercion will be any more effective. The poor do not have to be forced to work; they almost uniformly express the desire to work and demonstrate the sincerity of that desire on a daily basis by taking low-paying jobs with little autonomy or benefits. Like members of the middle class, the working poor need jobs that provide a living wage and that provide them access to basic health care and other human services that would allow them to maintain their basic dignity.

One of the motivations for requiring the recipients of cash assistance to work was the belief that working parents are better role models for their children. Hardly anyone would argue that a family in which one or both parents work at a good job is better off in every regard than a family that must rely on charity. But work that by its very nature undermines self-confidence and undermines family stability and routines may well undermine the goal of strengthening families. Although our focus is primarily on health insurance, the issues of poverty, like the issue of race, simply cannot be ignored. Our study led us to conclude that, to a large extent, the failure of the old AFDC cash assistance system, and the potential failure of the reformed system, results from the failure of public policy to deal adequately with the nonwage elements of work and the noneconomic aspects of poverty and family life. Among the most important of those is health and inadequate health care coverage.

Someone's Care Must Be Sacrificed

The incomplete system of coverage that we observed required that families engage in a form of medical care triage on their own. Although mothers were usually successful in enrolling their children in Medicaid, albeit often with frequent lapses, they were likely to neglect their own health and often did not get the medical care they needed because they

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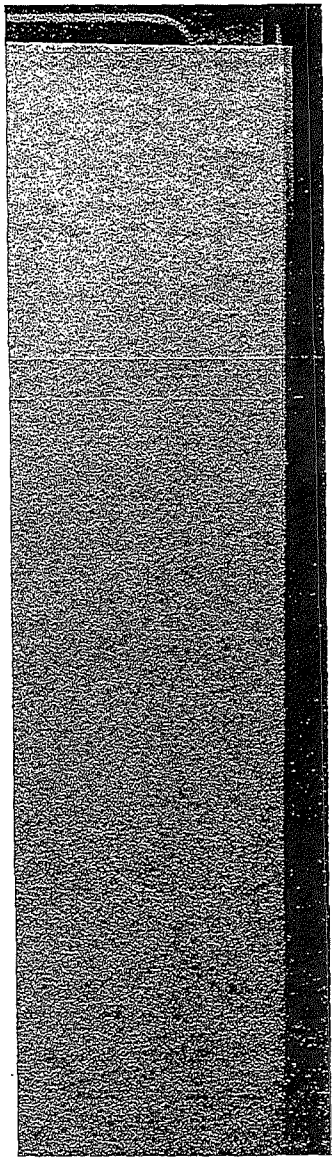

cherishes its U.S. citizenship, and those who are not citizens struggle to become Americans. Mexican Americans, and even Mexican nationals, have fought in all of America's wars, and many have moved into the economic and social mainstream. Yet, like African Americans, the unique history of the Mexican-origin population in this country has not included full economic and social incorporation for the group as a whole. Many Mexican-origin individuals in the United States remain outsiders to at least some degree. Some, of course, arrived only recently, and others are undocumented immigrants who live among us just below the surface of everyday life. Their marginal status is not surprising. Yet even for many of those who have been Americans since Texas and the rest of the Southwest became part of the United States, full incorporation has not occurred. Mexican American education levels, incomes, and personal wealth remain far below those of the majority non-Hispanic white population (Angel and Angel 1997; Grogger and Trejo 2002; Suro 1998).

Downtown San Antonio is dominated by hotels, museums, tourist attractions, and office and municipal buildings. The municipal core is only a mile from one of the poorest neighborhoods in the city, in which we carried out part of our study. Unlike the Midwest, San Antonio's economy was never defined by large smokestack manufacturing. In the years after World War II, some small-scale manufacturing jobs were available, but most of those have disappeared. Plants ranging from a blue jeans factory to a meat packing plant have closed since the 1990s, leaving the city largely dependent on tourism, health care, and the service sector for its economic base. Military installations continue to represent an important part of the local economy.

As in Boston and Chicago, neighborhoods differ from one another even when they share a basically similar socioeconomic profile. One defining characteristic of many San Antonio neighborhoods is the presence of large low-rise public housing projects and other apartment-style low-income housing. Some of our study neighborhoods were defined by such projects, whereas others included more single-family houses and private apartments. A few of our San Antonio families lived in The Courts, a public housing project that covers close to three-quarters of a square mile less than a mile from downtown. The Courts, however, like most San Antonio developments, differed from the old high-rise apartment complexes that are typical of Chicago and Boston. San Antonio projects more often consist of street after street of one- or two-story

buildings that contain small apartments. The Courts is one of the oldest housing projects in the south, originally dedicated in a ceremony attended by then First Lady Eleanor Roosevelt. During the hot San Antonio summer, doors and windows stand open because the apartments are not air-conditioned and indoor temperatures reach well over one hundred degrees. Many of the small yards in front of the housing units contain small flower gardens and wading pools that are among the few sources of beauty and recreation visible.

Most residents stay fairly close to home, except when they are forced to travel for work, to shop, or to obtain services. We met families whose school-age children had never been to the nearby downtown. Public transportation was inadequate and often involved a long walk to an inconveniently located bus stop. The city has no commuter train or subway system, and getting around the city is a constant problem for poor families. Although San Antonio is home to a major university health science center, its health care resources are concentrated on the outskirts or downtown and families using them must take long trips on public transportation. The only grocery store serving the same neighborhood is a small bodega, or what might be characterized as a mom and pop convenience store, although a supermarket opened roughly a mile away during the time of our study. At a somewhat greater distance, one could find a clinic that accepted Medicaid. To shop for major items or to obtain care for serious health problems, residents have to travel beyond the immediate neighborhood, which almost always represents a major effort. For the most part, only the most basic medical care is locally available, and our respondents used public transportation or found a ride to get to the doctor or clinic. Because most of our families did not own a car, their limited access to transportation also restricted the jobs they could take.

Chicago

Far to the northeast of San Antonio lies Chicago, in the agricultural and manufacturing heartland of the nation. As is the case in most American cities, in Chicago the movement of manufacturing jobs overseas means that the service sector accounts for a growing proportion of jobs, especially for the poor and those who have recently arrived. More massive and older urban structures and a longer, gray winter give Chicago a very different feel than San Antonio. Chicago provides a real sense

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of the intensity of urban America. Although San Antonio is home to nearly half a million individuals who trace their lineage to Mexico, the fairly recent migration of Mexicans to the Midwest has given Chicago an even larger Mexican-origin population (Guzmán 2001; Suro and Singer 2002). The city's Mexican-origin population is second only to that of Los Angeles in size. The city also contains large Puerto Rican and African American populations.

Chicago has been likened to a mosaic because of the clear distinctions among its many neighborhoods. As immigrant groups arrived, they occupied particular parts of the city and gave each its unique identity, in addition to well-defined boundaries. Like the Poles, Croatians, Lithuanians, Italians, and other groups who in years past lived in the same neighborhoods, the relatively new Mexican arrivals have redefined Pilsen/Little Village, one of the neighborhoods where we worked, which stretches from the Chicago River on its eastern border to the city limits on its western edge, and from around 16th Street on its north side to the Stevenson Expressway on its southern edge. This area is clearly a Mexican domain but one that exists in a physical environment very different from that of the Southwest.

Today, Chicago has a complex economy that includes manufacturing and service jobs. It is also home to several medical schools with associated teaching hospitals and clinics. Nevertheless, like San Antonio, it does not have the rich assortment of neighborhood clinics and health services available in many Boston neighborhoods. Unlike San Antonio, however, the city has a highly developed and dependable public transportation system, and getting to services is relatively easy. Given the clear dominance of local neighborhoods, most of the residents of the neighborhoods we studied stayed close to home and ventured out of their local neighborhoods only for services that were not available close by. When they had to travel, they had access to relatively straightforward transportation that, unlike San Antonio, made the use of services easier.

Boston

Boston, one of the nation's oldest cities, has always been racially and ethnically diverse, but today it is taking on the new Latino flavor. The city has a growing Hispanic population that is primarily Puerto Rican and Dominican. It also has a large African American population. As in other cities, Hispanics and African Americans are concentrated in the poorer neighborhoods, such as Roxbury and Jamaica Plain. Although with Chicago and San Antonio it shares many of the characteristics of larger cities, including the racial/ethnic concentration of poverty in particular neighborhoods, it is unique in many important ways. Perhaps most notably, it has a greater diversity of jobs. Service-sector job growth has certainly outpaced that in any other sector, but the city and surrounding region also offer opportunities for employment in light manufacturing and the high-tech industry. Unfortunately, few of these opportunities were available to our study families.

The Boston area includes numerous colleges, universities, and technical education centers, and it was an early center for the high-tech industry. The city's economy also depends on an extensive tourism industry driven by the numerous historical sites related to the nation's colonial period. It is also a national health research and education center with numerous medical schools, hospitals, and specialty clinics. Despite adopting relatively stringent welfare reform regulations, Boston has historically embodied a progressive political tradition and a generous social welfare philosophy. The city offers the poor a wealth of health and child care options, educational programs, and other assistance programs at the local level. The city has an efficient and extensive public transportation system, and getting to services was relatively easy for the respondents in our study. Housing is very expensive in Boston, and poor families rely on government subsidies for housing to a larger extent than in Chicago or San Antonio.

Roxbury, a traditionally black community south of the downtown area, is made up of distinct neighborhoods that range from deeply impoverished areas to areas occupied by middle-class families. A walk down any street in a low-income neighborhood in Roxbury reveals a range of housing. One public housing project, "The Blues," in which we conducted some of our interviews, consists of a series of buildings four to eight stories high that are connected by paved walkways. Although Boston, like Chicago, is moving away from its earlier reliance on high-rise public housing, the newer housing still consists of a series of shorter towers with interior hallways and elevators that can be dark and frightening. In Boston, projects are categorized in terms of the neighborhood in which they are located and by whether they are the old-style

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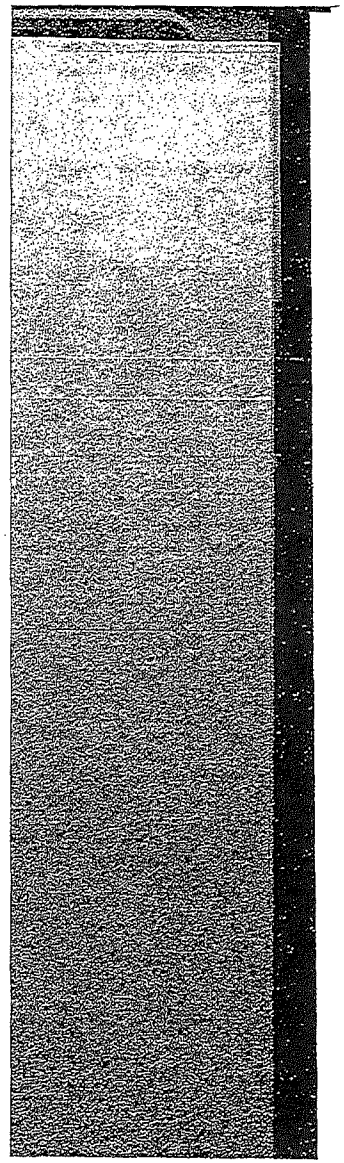

high-rise or one of the newer townhouse designs. The taller buildings are part of the older public housing stock that is still in use. During the 1970s and 1980s, the massive high-rise projects a few miles away in Dorchester were transformed into mixed-use facilities. Despite all of the changes that have occurred in public housing and in Boston neighborhoods, those in which we conducted our interviews revealed a great stability. The mothers in our study grew up in or near the same neighborhoods in which they now live with their children.

The Blues offers its residents many local conveniences and services. The project is located about a block away from a commercial area that includes a number of shops, ranging from beauty salons and restaurants to music and clothing stores. Half a mile away, there is a more extensive business area with grocery stores, a number of different human services agency offices, and a health clinic. The intermediate area is quite varied and includes several blocks of large, renovated Victorian houses in a neighborhood that has been gentrified. As is the case for most Boston residents, public transportation is readily available. Within two and a half blocks of The Blues, a subway station connects the project with the rest of the city. The subway line that serves this neighborhood goes directly to the downtown area and then on to Cambridge and other outlying areas. Although the subway system is built on a hub-and-spoke model and often requires transfers to complete a journey, the speed of the subway and the short connections reduce the travel time necessary to reach many services. The large teaching hospitals in Boston and their multiple clinics are easily reached by subway. Although Boston is also served by a bus system, the subway provides a speedy and often more useful alternative.

Three Different Political, Cultural, and Social Environments

As these portraits reveal, our three cities are very different in their physical and social environments. The state policies that govern their welfare programs are also about as different as possible. Massachusetts represents one extreme in the generosity of its welfare programs and Texas the other in the extent of limitations on eligibility and the extent of coverage of the population in need. Yet, as we explain in this chapter, we found through our ethnographic interviews that the realities of poverty and the challenges inherent in dealing with welfare bureaucracies

largely overwhelmed these differences. Although families in San Antonio were considerably more likely than families in the two other cities to experience periods without health care coverage, in all three cities families shared many of the same frustrations and difficulties that seem to be an inevitable part of dealing with the means-tested public health care system, as well as other welfare bureaucracies. Regardless of where they lived, our families were remarkably similar in terms of their health levels and the irritations and frustrations they faced in obtaining and maintaining family health coverage. One San Antonio case was typical of stories we heard in all three cities.

Natalie

During one of our early interviews with her, Natalie, a Latina mother of three daughters who was in her thirties, described what it was like to go through the process of recertification for Medicaid. With considerable exasperation, she said "I've got to plan a whole day just to go and do this . . . because it takes so long!" One day she had an eight-thirty appointment to meet with her social worker to recertify her Medicaid eligibility. When she arrived at the office, she turned in the paperwork she was required to bring and sat down to wait with all of the other parents who also had eight-thirty appointments. After a long wait, someone came into the waiting room and called the names of those who were to be seen first, including Natalie. That group was ushered into a classroom where they were required to listen to a lecture on Medicaid that covered eligibility criteria and a range of other matters. After the presentation, each parent was called in to see the caseworker individually. As Natalie noted, "You're lucky if you're the first one called by your caseworker. If you're not, you have to wait until he goes through all the clients and gets to you." If you are one of the last called, you can wait all day, as Natalie had often done.

Depending on the nature of the administrative problem she was facing, Natalie was sometimes able to request what she called an "individual appointment" with her caseworker. When she managed to get such an appointment, she did not have to listen to the lecture on program rules before seeing her caseworker. Also, when she had a fixed appointment she felt more justified in complaining if she had to wait too long because she had to take time off from work, travel to the welfare office, and give up needed income. Of course, she explained,

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any complaint usually fell on deaf ears. Individual meetings with her caseworker, however, usually went routinely, and after processing the necessary paperwork Natalie could be on her way. Even short and efficient meetings, however, were disruptive and required time off from work. The recurring need to recertify each of her children separately was stressful and time consuming, and the effort was not always successful. The application and recertification procedures for the programs she used required that Natalie miss a lot of work and, as was the case for other mothers in our study, she had to placate her supervisor and on occasion she ran the risk of losing her job.

Natalie, in fact, did lose her job because of health problems, and then in a cruel bureaucratic irony almost simultaneously lost her own Medicaid at a time when she needed it most. The circumstances surrounding the job loss and the loss of her Medicaid were complex and began when she had to have a hysterectomy because of extensive bleeding that was the result of uterine tumors. On this occasion, the fact that Natalie was employed worked to her disadvantage. As part of the Medicaid recertification process, she had recently reported her income to the Medicaid office and lost her eligibility because with her slightly increased income she no longer met the means test. Unfortunately, just as she lost her Medicaid she was fired as the result of excessive health-related absences. The income-based payment plan we mentioned earlier was her only real alternative for paying for her health care, and she used it when she could. However, without insurance and without a job, she was forced to take out a loan to pay her medical bills. For poor families such as Natalie's, one problem often precipitates a number of other problems that culminate in a catastrophic outcome.

Like so many others in her situation, Natalie had a checkered work history, and none of her jobs provided health insurance either for herself or her children. Although her daughters were periodically on Medicaid, Natalie had coverage for herself only during her pregnancies. After graduating from high school, Natalie began working as a full-time cashier at a department store, but she left that job when she was accused of stealing. She took another job at a bowling alley, but once she had divorced her first husband, she could no longer support herself and her daughter on the salary that job paid. She then took a better-paying job at a pawn shop. In this new job, Natalie had to leave her youngest child with a friend because she had to work until 5:30 P.M., after which she had an hour commute. She could not find other child care that would allow her to pick the child up as late as 6:30 P.M. She lost the job at the pawn shop when she had her hysterectomy.

In light of the gravity of her health problems, and in order to help the family out while Natalie was jobless and ill, her partner, the father of her second child, moved in with her. This precipitated yet another crisis because the family was living in subsidized housing that did not allow another adult to move in, especially an adult male who in the eyes of the authorities should support the family. When the partner's presence was discovered, Natalie and her daughters were evicted and she had to move in with her mother. While she was living with her mother and recovering from the surgery, she tried to find work. She was particularly worried about paying back the large debt that she incurred as the result of her operation. Throughout this period, Natalie was also trying to help her grandmother, who had recently moved to San Antonio from Mexico City. The old woman, who had been ill, died toward the end of the time that we were in contact with Natalie, and the loss represented yet another negative event that added to the chaos of her family life.

Some months after these events, Natalie found a new job at a different pawn shop and slowly began to get back on her feet. Shortly afterward, however, she injured her back and knee during a particularly strenuous day of moving and lifting, and she was unable to get out of bed the next morning. Although her doctor prescribed therapy for the job-related injury, she was still without health insurance and her employer would not pay for the treatment. Nearly destitute and in need of treatment, Natalie managed to qualify for Medicaid for a twelve-month period. Despite almost constant back pain, she had to get to work and also get to her therapy appointments. Her mother tried to help, but Natalie worried that her mother might well lose her own job if she took too much time off from work to help out.

Natalie often experienced moments of discouragement and felt that she was only barely living up to her responsibilities. With so many crises in her life, she often felt little hope for the future. She could only dream about the impossible luxury of a vacation and a respite from all of the demands of her life. Fantasizing, she told us, "I'd like a hotel room somewhere for a week where I could take hot baths with candles and music to help me relax." But she continued with her daily routine, hiding her worries from her mother and children. She admitted that

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whatever semblance of normal feelings she displayed was just a front to hide her real desperation: "I keep my face strong, so nobody will know I am weak. It's a bluff."

Would It Be Different in Another City?

Natalie lived in Texas, a state with some of the weakest supports for poor families in the country and the one with the highest proportion of uninsured citizens in the nation. As we described, San Antonio provides only limited public transportation, and getting to health care and other services is difficult and time consuming. We have argued that Texas serves as the extreme example of the consequences of the limited programmatic support for poor families that are increasingly part of limited budgets and public hostility to welfare. This hostility resulted in competition among states to limit benefits, resulting in what some have described as a "race to the bottom" (Albert and Catlin 2002). Although poor families in San Antonio faced particularly serious problems related to transportation and very low welfare payments, families in Boston and Chicago were in reality no better off, especially because the cost of living is so much higher in those cities. The three cities in our study are all large metropolitan areas in states with very different welfare policies, and our objective was to determine how that variation might affect families' experiences with health care and health insurance. In addition to differences in welfare policies, the cities were chosen because they represent three important regions of the country, with unique labor markets, and unique mixes of metropolitan resources such as public transportation and housing, and unique health service environments. They also differ in their racial and ethnic compositions, a consideration very important to our objective.

San Antonio has a large and growing minority population and according to census figures is 58 percent Hispanic, and these Hispanics are primarily of Mexican origin (Guzmán 2001). Although nearly half a million individuals of Mexican origin live in San Antonio, Chicago's Mexican-origin population is larger as a result of increasing immigration since 1960. Boston has a large and growing Puerto Rican population, as does Chicago, but its Hispanic population also consists of Dominicans, Salvadorans, Mexicans, and other Central and South

Americans (Boston Redevelopment Authority 2001; Gusmán 2001). Chicago and Boston have larger African American populations than does San Antonio, although all three cities contain large numbers of African Americans, who reside mostly in minority neighborhoods, and like much of the rest of the United States, all three cities include growing Asian populations (U.S. Bureau of the Census 2000).

In this chapter, we compare the cities in terms of the completeness of health care coverage for poor families using data from the Three City Study survey, examine the broad social and economic environments of the three cities, and summarize differences in their eligibility rules for Medicaid and other health programs. We present data from the ethnography that illustrate the difficulties families face in maintaining continuous coverage in all three places. The ethnographic data reveal the ongoing struggle required to maintain health care coverage and the relative disadvantage of powerless individuals in dealing with complex, and what at times seem like arbitrary and hostile, bureaucracies. The differences that emerge among the three cities relate not only to their different welfare policies but also to geography, the local transportation and health care delivery systems, and the local labor market. Although state welfare policies, including those related to health care, differ in important ways, no matter where they lived, our families faced difficult challenges in maintaining public health coverage for the whole family even when they qualified for it initially. Once again, the data make it clear that the core problem arises from the lack of a universal health care system and the reliance on employer-based health insurance in the nation as a whole.

Boston families in the ethnographic sample had far fewer problems with continuity of health insurance than did San Antonio families. This seemed to be related primarily to the far greater generosity of MassHealth, the Massachusetts Medicaid program that covered children up to 200 percent of the federal poverty line (FPL) and their caretakers up to 133 percent of the FPL. In addition, in Boston, a somewhat larger number of families than in Chicago or San Antonio had access to some level of employer health care coverage. The causes of discontinuities in coverage also differed between Boston and San Antonio. In San Antonio, our families experienced periods of ineligibility because of more restrictive eligibility criteria as well as a lack of coverage when paperwork did not flow smoothly. Boston families experienced

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discontinuous health care coverage of shorter duration primarily when there was some difficulty with the paperwork. Chicago families' experiences fell somewhere between those of families in Boston or San Antonio.

Even in Boston, however, health care coverage for families was neither seamless nor administratively simple. Although the range of care covered was broader than in Texas, it had some important limitations. In all three cities, families lacked coverage for eye care and glasses, and they had only limited dental coverage. Although Massachusetts was unusual in providing treatment for at least some mental health conditions, no state provides public insurance coverage for all mental health conditions or all of the treatment they require. Because of Texas' historically restrictive welfare policies, even before welfare reform San Antonio embodied the new national mood that has changed the context of welfare and health care for low-income families. Texas and San Antonio moved toward more restrictive policies well in advance of the federal legislation through the use of waivers (Capps et al. 2001). As we have noted, in many ways Texas represents the logical culmination of the process of devolution in a time of restricted budgets. Without a state income tax and in the face of the post-2000 economic slowdown, the insurance situation for the poor in Texas deteriorated (Dunkelberg and O'Malley 2004; Smith, Rousseau, and O'Malley 2004). Although the retrenchment may have been more pronounced in Texas than in Massachusetts or Illinois, similar changes were introduced in those states as well, largely mandated by federal law but also reflecting state initiatives. All three cities therefore embodied the new opposition to cash assistance and time-limit preferences that spread across the nation in the 1990s. As a result of welfare reform, all three cities experienced a significant retrenchment in eligibility for welfare and other public benefits. At the same time, all three cities experienced declines in manufacturing employment and a growth in the proportion of low-wage service-sector jobs (Anari and Datzour 2004; Boushey and Rosnick 2004; Kalleberg, Reskin, and Hudson 2000).

The Drop in Medicaid Coverage after Welfare Reform

After the implementation of federal welfare reform in 1996, Illinois, Massachusetts, and Texas experienced dramatic drops in Medicaid

enrollment, as did every other state (Chavkin, Romero, and Wise 2000; Committee on Child Health Financing 2001; Ku and Bruen 1999; Rowland, Salganicoff, and Keenan 1999). This decline occurred even as states increased spending on Medicaid and in spite of the fact that the majority of children who were not enrolled qualified on the basis of income (Holahan and Bruen 2003; Kohn, Hasty, and Henderson 2002; Rowland, Salganicoff, and Keenan 1999; Starfield 2000). This drop in Medicaid was a clearly unintended consequence of welfare reform, the objective of which was primarily to limit cash assistance. In response to the fact that many children in near-poor families do not qualify for Medicaid, Congress provided funding for the State Children's Health Insurance Program (SCHIP), which offers coverage to children not eligible for Medicaid because their family's income is too high. All three states now have an operating SCHIP program, although during the time of our study Texas was just beginning to enroll children.

Even after the introduction of SCHIP, however, many eligible children remain uninsured (Chavkin, Romero, and Wise 2000; Dubay, Haley, and Kenney 2002; Kohn, Hasty, and Henderson 2002; Ku and Bruen 1999; Salsberry 2003; Weinick and Krauss 2000; Zuckerman et al. 2001). Although Texas finally began enrolling children in SCHIP, the state has since dropped children from its SCHIP program because of serious state budgetary shortfalls. In 2003, the drop in Texas' SCHIP enrollment was in fact so dramatic that it resulted in a national decrease in the number of children covered (Dunkelberg and O'Malley 2004). As our ethnographic data reveal, even the rather dramatic statistics concerning the number of uninsured children in all three cities do not fully reveal the true extent of the problem of incomplete and inadequate health care coverage for either children or adults. As we reiterate throughout this book, families in all three cities faced the recurring problem of frequent, if relatively short, lapses in coverage because of bureaucratic roadblocks or errors.

State Medicaid Policies

In all states, in order for a child to qualify for Medicaid, his or her family had to fall below income thresholds that vary with the child's age (Health Care Financing Administration 2000). By 2003, states were required to cover all children under nineteen in families with incomes

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below 100 percent of the federal poverty line (FPL), although not all states had done so at the time of our study. At the time we were recruiting families, the federal government required states to cover children less than six years of age in families with incomes below 133 percent of the FPL. Even today, although the federal government sets the basic eligibility standards, the states retain a good deal of discretion in setting eligibility standards and payment levels within those federal mandates. As a consequence, the Medicaid eligibility requirements for children in Illinois, Massachusetts, and Texas differ significantly. As of July 2000, while we were carrying out our interviews, Illinois covered infants less than one year of age in families with income at or below 200 percent of the federal poverty line. In that state, children up to nineteen in families with incomes below 133 percent of the FPL were also covered. Massachusetts covered infants at or below 200 percent of the FPL, whereas older children nineteen and younger were covered at or below family incomes of 150 percent of the FPL.

Texas had far more restrictive eligibility policies than either Illinois or Massachusetts for older children (Capps 2001; Ross and Cox 2000). In Texas, infants below one year of age were eligible for Medicaid if they lived in families with incomes at or below 185 percent of the FPL. Children between the ages of one and five qualified only if their family's income fell below 133 percent of the FPL, and children between six and nineteen years of age were eligible only if their family income was below the federal poverty threshold. Caregivers were excluded from Medicaid unless they were receiving SSI, were disabled, or were pregnant (Health Care Financing Administration 2000; Strayhorn 2001). Texas formally covered the medically needy, but the income and asset limits required to qualify were extremely low. The state did not have a state-financed health coverage program for families that did not qualify for Medicaid. Rather, it relied on public hospitals run by the counties to provide indigent care. In 1997, the Texas Healthy Kids Corporation, a public/private partnership, began providing health insurance to nearly 1.3 million uninsured children ages two through eighteen. Although this program required that a family pay a monthly premium for each child covered, it also offered assistance through private funding in paying the premium for families with low incomes. During the 2001 legislative session, Texas passed legislation to simplify the application procedure for Medicaid.

In contrast with Texas, Massachusetts has attempted to cover as many poor families as possible, often at state expense. Under a federal waiver, the state greatly expanded its coverage of the poor through MassHealth. This program covered pregnant women and infants less than one year of age in families with incomes below 200 percent of the FPL and all children up to age nineteen in families with incomes below 150 percent of the FPL. The state's SCHIP program is part of MassHealth and was approved in 1998 with a retroactive start date of July 1997. Massachusetts also provides health care coverage to the poor and unemployed through several other state-funded insurance programs, including an uncompensated care pool that provides coverage for hospital care. As a result of its generous policies, Massachusetts is one of the states with the highest rates of health insurance coverage and most extensive health safety net for the poor. Evidence of this was clear in the decreased frequency and shorter duration of our Boston families' lapses in health care coverage. However, the more generous coverage did not entirely prevent periods with no insurance, nor did it address the lack of coverage for serious ongoing conditions. Our sampling design, including the selection of families with income at no more than 200 percent of the FPL, meant that in Boston we did not include families just over the threshold for some Medicaid coverage, those that would have been the most likely to experience periods with no medical coverage.

Prior to 1998, Illinois did not extend Medicaid eligibility beyond the federal requirement, covering children up to age six in families with incomes below 133 percent of the FPL and children up to age sixteen in families with incomes below the FPL. The state also covered teenagers in destitute households, which includes those with incomes below 50 percent of the FPL. Illinois' SCHIP program, KidCare, began in 1998 and expanded the number of eligible children in families with incomes below 133 percent of the FPL. At the time of the study, all children under nineteen years of age in these families were covered. Infants under one year old were covered in families with incomes up to 200 percent of the FPL. Illinois has a program for the medically needy to assist low- to moderate-income families that incur large medical expenses. As a consequence, families in Illinois experienced shorter lapses in coverage than families in Texas and were covered for more ongoing conditions.

TABLE 4.1. *Focal Child and Caregiver's Insurance Status, Wave 1 (Percentages)*

Caregiver's Insurance Status	Focal Child's Insurance Status: Employer or Union	Private/ Military/Other	No Insurance	Medicaid	Row%
Employer or Union	62%	2%	22%	14%	19%
Private/Military/ Other	5%	40%	4%	50%	6%
No Insurance	10%	1%	84%	5%	11%
Medicaid	1%	2%	0.2%	97%	64%
Column%	14%	4%	14%	68%	100%

The Extent of Health Insurance Coverage in the Three Cities

Our three states differ in potentially significant ways in eligibility criteria as well as other aspects of their Medicaid and SCHIP programs. Table 4.1 presents information from the Three City Study survey on the health insurance coverage for the caregiver and the focal child for whom we have extensive information from the first wave. The table compares different combinations of insurance coverage for the caregiver, who is in the vast majority of cases the focal child's mother, and the focal child. The table shows, for example, that among those caregivers who were covered by an employer-sponsored plan (19 percent of the sample), 62 percent of focal children were also covered by that plan. On the other hand, 22 percent of those children had no coverage of any sort and 14 percent are on Medicaid. When the mother had some other form of nongovernmental insurance, 40 percent of the children were covered by that plan and half were on Medicaid. Among those mothers with no insurance, the vast majority of their children also had no insurance. Given our selection criteria for the age of the focal child, 0–4 or 10–14, many of the mothers were still covered by Medicaid, which covers pregnant and nursing women, and in those cases so were nearly all of the focal children.

As in other studies, a large percentage of children in the Three City Study had no insurance. But the risk of lacking insurance differed significantly for different racial and ethnic groups. Figure 4.1 compares the percentages of children in our sample who have no health insurance of any sort for the different racial and ethnic groups in the study. The most striking finding, and one that is consistent with most previous

TABLE 4.2. *Percentage of Children Covered by Medicaid*

Family Income Relative to Federal Poverty Line	All 3 Cities	Boston	Chicago	San Antonio
<100%	77%	82%	82%	64%
100–124%	58%	86%	59%	30%
125–149%	53%	63%	61%	35%
150–199%	34%	64%	35%	5%

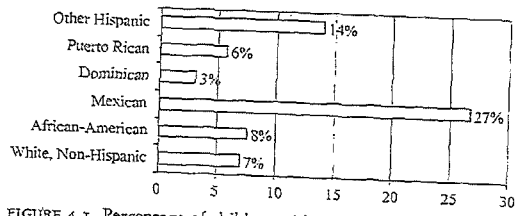

FIGURE 4.1. Percentage of children with no health insurance by race and Hispanic ethnicity

research, is the astonishingly high proportion of Mexican-origin children who have no coverage. Twenty-seven percent of the Mexican-origin children in our survey sample have no private or public coverage. For African Americans, this figure is 8 percent, and for non-Hispanic whites it is 7 percent. Clearly, this low rate of health insurance among Mexican-origin children represents a serious social problem. Even if these children receive charitable care or care from an emergency room, they do not have the one resource that might help assure continuity of care. These data make it clear that although in the United States we have a serious problem of lack of insurance among the poor, the problem is seriously confounded with aspects of race and Hispanic ethnicity.

In order to investigate the impact of state policy differences on Medicaid coverage, in Table 4.2 we present information on the proportion of children who were receiving Medicaid for different levels of family income expressed in terms of the ratio of family income to the federal poverty level (FPL). This table shows that while 77 percent of children in families with incomes below 100 percent of the FPL were covered in the sample as a whole, the proportion of children in these poorest families who were on Medicaid differed greatly among

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TABLE 4.3. *Percentage of Focal Children and Caregivers Who Did Not Receive Needed Medical Care by City*

	City		
	Boston	Chicago	San Antonio
Focal Child	3%	5%	12%
Caregiver	7%	13%	18%

the three cities. Eighty-two percent of these children were covered in Boston and Chicago, but only 64 percent were covered in San Antonio. As family income increased, Medicaid coverage dropped in all three cities, but the drop was particularly pronounced in San Antonio. Among families with incomes between 150 percent and 200 percent of the FPL, only 5 percent of children were enrolled in San Antonio compared with 64 percent in Boston.

These city comparisons show how Medicaid coverage is related to state policy. At the time of the survey, Massachusetts had instituted the required and most of the optional coverage options provided by federal law. Texas, on the other hand, had not, resulting in the low coverage among families with incomes over 150 percent of the FPL, the income range in which states retained the greatest discretion as to whether to extend eligibility. These differences in coverage translated into differences in the use of health services. In the first wave of the survey, we asked respondents whether during the twelve months preceding the survey they had gone without health care they needed because they could not afford it. Table 4.3 shows that the percentage who reported going without needed care was higher for both the caregiver and the focal child in San Antonio than in Boston or Chicago. Boston's policy of maximizing coverage led to a lower proportion of caregivers who were forced to go without needed care in that city than in either of the two others.

State Medicaid Policies and Barriers to Health Care

Our study revealed three major barriers confronting low-income families in the struggle to get and keep health insurance in all three cities. The first barrier was the means-tested nature of public health insurance programs, for which one had to establish and reestablish eligibility.

Only families below certain income levels or those with slightly more income that include someone with a serious qualifying health problem could receive Medicaid. The second barrier arose from bureaucratic hurdles faced even by those families that were eligible for Medicaid. Families had to apply for each member of the household individually, recertify each one as required, and meet the constraints on "appropriate" use of medical services. In Chapter 3, for example, we introduced Darlence, who was threatened with reduced coverage if she continued to "overuse" her Medicaid by making the many appointments required by her complex medical conditions. The third barrier arose from difficulties families faced in locating a provider who would accept Medicaid even after they qualified, as well as securing transportation to that office or clinic. Given low Medicaid reimbursement rates and the bureaucratic effort required of providers, many physicians do not participate in the Medicaid program.

One might expect that as welfare policy, including that related to health care, has devolved to the states differences in how states choose to exercise their greater autonomy might mean that one's state of residence has a significant impact on the range and amount of health care a family receives. Although there have always been important elements of health care policy for the poor that have been determined at the state level, today states have even more control over the determination of eligibility, the nature and complexity of the application and recertification process, and the extent of services provided. Although states differ in their response to devolution, all state plans are still means-tested, bureaucratically complicated, and do not cover all conditions or all individuals and households in need.

In our study cities, as in cities across the nation, one's neighborhood, as well as the city and state, can affect the amount and type of health care available. A neighborhood with a free community health clinic or one with an emergency room that serves the neighborhood provides more opportunities for a poor family to get care than a neighborhood without such health care resources. In addition, transportation difficulties, especially in cities like San Antonio, which is widely spread out and has a poorly developed public transportation system, directly affect a family's access to health care, especially if they live far from available services. Helen, one of our San Antonio respondents, explained that her family owned a car even though they could hardly afford it. Car

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ownership by families on welfare has been a long-standing criticism of the system and often used in caricatures of welfare cheats, but in cities that have been defined by the car and that have minimal public transportation, the lack of an automobile can mean serious isolation. Even though she owned a car, whenever possible Helen's family used public transportation to get where they needed to go, including the doctor's office. There were times, however, such as when her daughter's asthma became severe, that public transportation was just too slow and inconvenient to be a viable option. For poor families that own a car, social program asset tests can produce a veritable catch-22 because ownership of a car worth over $2,000 can make a household ineligible for some welfare programs. Ownership of a car often represents as much of a burden as it does a useful asset. As our respondents pointed out to us, cars that are worth less than $2,000 tend to be unreliable and very expensive to operate.

Other geographic and neighborhood factors influence the availability of and access to health care as well. The size and layout of particular neighborhoods can make a difference in and of itself. Western cities like San Antonio are spread out over a large area. A block in San Antonio, especially in residential areas, is usually much larger than a block in Chicago or Boston. Neighborhoods and specific socioeconomic areas within the city can be huge, as are the Mexican and African American neighborhoods we studied. In San Antonio, distances from home to work, to the supermarket, to school, to the day care center, to churches, to the clinic, or to the welfare office can be great. The newer cities of the West never developed subways or train systems, and their bus service to certain areas remains inadequate. In San Antonio, getting to the welfare office, to work, or to the doctor on public transportation often requires multiple bus transfers and several hours of travel time. Many of our families in San Antonio, like Helen, used health care services that were on the other side of the city, and getting there and back without a car could be an all-day ordeal. In Chicago and Boston, on the other hand, neighborhoods are better-defined and less spread out. Both cities have multiple forms of public transportation, and getting around within the neighborhood and to other parts of the city is easier than in San Antonio.

In all three cities, policy and ecology worked interactively and in conjunction with culture and economics defined the environment within

which families succeeded or failed in their attempts to obtain adequate health care. We must once again stress the point, however, that despite significant differences among the study cities, they all shared the characteristic that families faced difficulties in acquiring and maintaining health insurance for all household members. Differences in state policies and in access to health care were often overwhelmed by the basic welfare nature of Medicaid and other public programs. Means testing was universal, and applying for publicly funded health coverage always involved a bureaucratic process that was often poorly understood by those trying to use it.

In the End, the Similarities Outweigh the Differences

Very early in the study, it became obvious that the poor share certain similarities regardless of the state or city in which they live. In the survey component of the study, we found relatively few substantial city differences in the general socioeconomic profiles of families. In each city, residents of the poor neighborhoods that we studied had low levels of education, they were unemployed or worked at low-wage, unstable jobs, they frequently cycled on and off welfare, and they had irregular access to health care coverage, which they easily lost when they were able to obtain it. The caregivers in these families suffered from poor health, they had disrupted relationship and marital histories, and they experienced frequent and extended periods of unemployment. These patterns reflect a complex interaction of personal traits, specific racial and ethnic group histories of exclusion and discrimination, basic structural aspects of the U.S. economy and labor market, and the nature of our health care system. Of course, many of the similarities among our three samples arise from the fact that we intentionally selected them from poor neighborhoods defined in terms of high levels of disadvantage and need.

Despite what might seem like significant state-level differences in policy, all three cities share in the reality that the social welfare programs on which their inhabitants depend are based on the means-tested safety net approach characteristic of U.S. welfare policy in general. All state programs operate within federally mandated limits and can offer additional services only at their own expense. Most importantly, in all three cities, the reliance on public programs is stigmatizing. Rather

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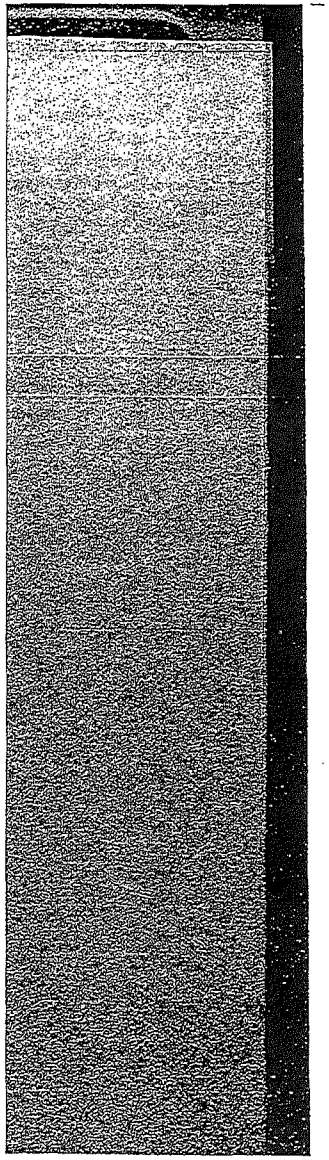

than receiving health care as a citizenship right or as an employment benefit, those families that rely on Medicaid must reaffirm their pauper status on a regular basis in order to continue to receive services. As our interviews revealed, the recipients of publicly funded social services, including health services, live with the daily reality of sanctions, rejection, and humiliation. Although Massachusetts was more generous than Texas, Medicaid in Massachusetts, like food stamps or housing assistance, is a welfare program. In both states, it shares in the general problem of welfare for the poor, which is a fundamental problem for the nation at large.

In our opinion, there is no good welfare model for health care. Health care, like education, should be provided as a citizenship right because the collective welfare of the nation depends on the health of its people. If the United States had a universal and comprehensive health care financing system, states and localities would not differ based on state policy or on the basis of their population's ability to pay. Currently, states and localities do not differ greatly simply because all public health programs share the same characteristic of being programs for the poor, and all of them are increasingly responding to budgetary constraints and a growing public aversion to means-tested programs. For that reason, the situation in Texas shares with Massachusetts or Illinois more than might be readily apparent in terms of the problems that welfare recipients faced at the time of our research and are likely to face in the future. Again, we must reiterate that a focus on the experience of poor Texans at the welfare and Medicaid office tells us a story about national possibilities as all states deal with rising Medicaid budgets and serious budgetary shortfalls.

The Working Poor and the State Children's Health Insurance Program (SCHIP)

As Natalie's story illustrated, her application for Medicaid required multiple visits to the welfare office and considerable documentation for each individual for whom coverage was sought. During the period we worked in San Antonio, families were required to reestablish eligibility in person for each individual every six months, and they were often required to provide additional documentation at these

times. For families with several children, families with children with serious health problems, or those in which parents had inflexible work schedules, the requirements for maintaining health insurance through Medicaid became serious obstacles both to continuous health coverage and employment. Legislative reforms have streamlined the application procedure to include mail-in applications and less frequent recertification requirements. During the time of the study, Texas, unlike the two other states, included assets in addition to income in the determination of Medicaid eligibility for children (Ross and Cox 2000).

All states currently operate an SCHIP program. Depending on each state's preference, its SCHIP program can consist of an extension of its Medicaid program, in which case it is required to offer the services offered under the Medicaid program, or it can consist of an entirely separate program that provides fewer services than Medicaid. During the time of our study, Texas' SCHIP plan had been approved but had just begun to enroll clients. In the two other states, the program was up and running. As with Medicaid, the eligibility criteria for SCHIP and the extent of the services covered differed among states. In Illinois, children in families with incomes at or below 185 percent of the FPL qualify for the program, whereas in Massachusetts and Texas the cutoff is 200 percent of the FPL. Although children in families with incomes up to 200 percent of the FPL qualify for SCHIP coverage in Texas, a large number of eligible children in that state are not enrolled, and in 2003 the state experienced a decline in enrollment so large that it resulted in an overall national decline even as thirty-seven other states had modest enrollment increases (Dunkelberg and O'Malley 2004; Smith, Rousseau, and O'Malley 2004).

Although states have the option of providing care to parents as part of their SCHIP program, as we shall see later, no public program covers the full range of health care needs of nondisabled working-age adults. In the United States, the primary route to health insurance is through employment, and as part of welfare reform and the new national mood, families are expected to leave welfare and become self-sufficient through work. Ideally, employment should provide health insurance coverage for the adult workers in the family as well as for the children. As we show in the next chapter, however, for workers at the bottom of the economic ladder, employment provides neither

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the wages that might make economic self-sufficiency possible nor the benefits that could replace the means-tested programs upon which poor families depend. As the cases we present in the next chapter show, because of the nature of the low-wage labor market and the highly restrictive participation criteria for many public programs, including those related to health, a family can find itself worse off once a parent goes to work than it was before.

5

Work and Health Insurance

A Tenuous Tie for the Working Poor

Despite the fact that most of the mothers on welfare we interviewed expressed a desire to work and to support themselves and their families, the reality of work in the low-wage service sector made self-sufficiency almost impossible. Many mothers in our study found that employment increased the difficulties they faced in maintaining a stable home life, and it frequently meant the loss of Medicaid. The objective of any rational welfare policy is to encourage work and to promote economic self-sufficiency and family stability. However, as we learned, in combination with the insecurities of low-wage work, the bureaucratic structures and rules that govern public support programs are often irrational and undermine the objectives they are intended to promote. In reality, few of our respondents were better off working than on welfare, yet most attempted to find employment whenever and wherever they could. Of course, as a result of welfare reform, they were required to do so, but most clearly would have preferred self-sufficiency over welfare dependency. The case of one young African American mother of four children illustrates many aspects of the work-related difficulties our respondents faced.

Sarah

Sarah, who we introduced in Chapter 2, had four children that ranged in age from three months to eight years. We conducted our initial interview in the family's small apartment, which was located in "The Courts," an old housing project close to downtown San Antonio.

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During the interview, we were constantly interrupted by children shouting and screaming, by incessant phone calls, by someone's changing of television channels, and by the comings and goings of any number of friends and relatives. Because of the heat, the windows had to remain open, and construction work at the school across the street increased the already high noise level that interfered with the flow of the conversation. All members of the family suffered from health problems, and Sarah's unpredictable work schedule at a local social service agency made it difficult to find time and energy to deal with them and the many other problems that were a constant part of life at the edge. Like so many other mothers in low-wage jobs, Sarah was required to work a different number of hours from one week to the next and was never quite sure what her schedule would be. Her job provided relatively little income and no benefits.

The multiple demands of her life, in combination with the crowding and noise at home, had clearly taken their toll on Sarah's emotional health. When we first met her, she was tired and discouraged. Although she was working and doing her best to become self-sufficient, she was unable to establish the routines that might have introduced some predictability and stability into her family life. Because of her low income, she was unable to move the family to better housing. According to her, the family's apartment was in the worst section of the projects, and she told us that "Most of the bad things in The Courts happen in this area." In addition to her job and the demands of caring for her children and maintaining the household, there were other demands on Sarah's time and energy. Her mother, who was ill with diabetes, lived about an hour and a half away by car. Although Sarah tried to offer some assistance to the older woman, the distance and the fact that she had no car made it difficult to visit or to provide the help her mother needed. Periodically, she would take the bus to her mother's house, but with four children the trip was expensive and tiring, and she often also had to take time off work to make the trip.

At one point, Sarah's sister, who had three outstanding felony warrants and nowhere else to go, moved in with the family for a short period. Just as she tried to help her mother, Sarah wanted to help her sister, but in order to do so she ran the risk of being evicted if her sister's presence was discovered. Her sister's presence not only added to the practical burdens faced by the family but also increased the general

tension level of the household. The constant stress no doubt contributed to the family members' health problems, and these were a constant worry for Sarah. Three of the four children had asthma, and the fourth was born three months prematurely and suffered from other lingering respiratory problems that required ongoing medical attention. Sarah did her best to get the children the care they needed, but without health insurance from work she had to make difficult choices. When we met her, the children were being cared for by a pediatrician Sarah liked, but the doctor's office was on the other side of the city and it took an hour and a half to get there by bus. Conflicting work demands and the time it took to get to the doctor's office meant that Sarah avoided taking the children to the doctor unless it was absolutely necessary. As we mentioned in our introduction to Sarah, the children did not get routine care, nor was it clear that they were up on their inoculations. When the children developed serious symptoms, Sarah somehow managed to get them to the doctor.

The family's ability to get health care was made more difficult by Sarah's sense of pride and her determination not to use the emergency room or the public school system for health care. She insisted that the children get their shots at the doctor's office, where she had more control, instead of at school, where a local clinic occasionally made them available. One bright spot in Sarah's life resulted from the fact that her pediatrician went out of her way to help the family. At one point, when the family did not have Medicaid, the doctor worked with her on a payment schedule. Sarah was very appreciative and told us, "She's really good . . . like in one case, [she said] 'I'm sending somebody over there to come get you.'" The pediatrician sent someone to bring Sarah and the baby to the office because the doctor thought the child needed to be seen immediately.

Sarah herself had no health insurance throughout the entire study period. She had held six jobs in the three years preceding our interviews, but none provided health benefits. Although she told us that she enjoyed her current job at the social service agency, it clearly fell far short of providing for all of the family's needs. The fact that she liked the job and wanted to keep it placed her in a difficult situation. If she did not want to be fired, she could not take off from work for the appointments required to apply for, and then periodically reestablish, each child's eligibility for Medicaid. At one point, the family had

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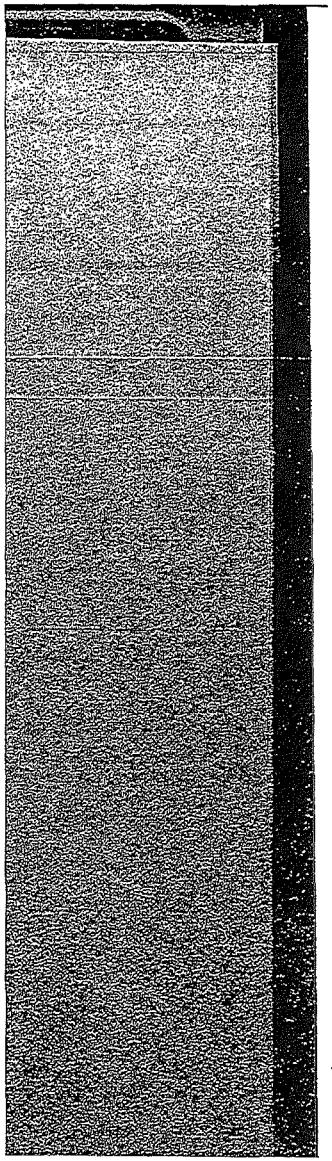

been dropped from Medicaid completely because Sarah had missed too many appointments. Because she had no other choice, Sarah finally made the work and income sacrifice required to apply for Medicaid, but the effort was not successful. Even though she kept her appointment, her application was denied because she failed to bring some supporting documentation. In order to avoid skipping work to bring the additional documentation to the Medicaid office, Sarah faxed the documentation from her job, but the fax was not accepted and her application was again denied.

At one point, when times got really hard, Sarah applied for emergency assistance, which, as she understood it, provided short-term support to those not on TANF. This program provided assistance with rent and with transportation expenses, but it did not address the family's health care coverage problems because it did not include eligibility for Medicaid. For Sarah, the need to seek such aid was humiliating; she felt that the caseworker did not believe her and even implied that she was not a good mother. She told us that the caseworker asked "Well how did you go four months without food stamps, Medicaid, or a job? How do you pay your bills?" Lacking any power or influence when confronting the bureaucracy, Sarah had no choice but to endure whatever the process meted out. As she said, "Every time you go in there it's a different change they've made. You spend a whole day down there. They want to know how many men, especially when you're doing the child support papers, man, how many times [you've had sex]! I mean it's so personal."

The confusion and difficulty that were part of applying for welfare and health insurance mirrored themselves in many other areas of the family's life. Work, rather than providing solutions to the family's problems, only complicated them. Sarah lived in a world of bureaucratic rules and regulations in which she was not an influential client to be courted and shown respect but rather a powerless pauper who had to beg for information and help from an intractable and unsympathetic system. Her job gave her no power or social standing. Her attempts to find better housing were a constant struggle and another example of the complexities of the bureaucratic system that she had to negotiate. The family had been on the waiting list for "Section 8" housing, the major housing subsidy program for the poor, for nine years. However, Sarah did not actually understand how the waiting list worked or that

she had to reconfirm her interest on a regular basis. When she failed to do so, she was dropped from the list, and when she finally called the Housing Authority to inquire about her position in the queue, she learned that she was no longer on the list at all.

Like all low-wage parents, Sarah had few resources, whether in terms of time, energy, or money, with which to deal with the demands of work and the requirements of the Medicaid bureaucracy or other parts of the welfare system. The demands that the combination of work and family life placed on her were often overwhelming and always demoralizing. During the last few months that we were in contact with the family, neither Sarah nor her children had health insurance. Her attempts to obtain coverage remained an ongoing struggle. For families like Sarah's, a successful application for Medicaid for one child can represent only a temporary victory. The coverage is by no means permanent, and because Medicaid does not offer full family coverage, each child must be qualified separately. Sarah's job could not provide her with the benefits or wages she needed. It was clear that she paid a penalty for her efforts to comply with her own and society's expectation that she work and attempt to support herself and her family. The problem, as our data reveal, lies in the structure of the low-wage employment market, which makes escape from poverty difficult and potentially undermines the health of children and adults. We will revisit Sarah later in this chapter.

Work Is Not Enough Even When You Can Get It

The families in our study provided many insights into just how weak the tie between work and health care coverage is for so many adults and children in the United States. Although most middle-class Americans have employer-based health insurance that covers all members of the family, those at the bottom of the income and occupational hierarchies, a population that like our sample is disproportionately African American and Hispanic, find themselves at best with episodic coverage or coverage for only some members of the family and at worst without any coverage at all. The families in our study were rarely offered employer-based insurance, a fact that was of little real consequence because few could have afforded the required employee contribution out of their low wages. Yet when they found work they faced a serious

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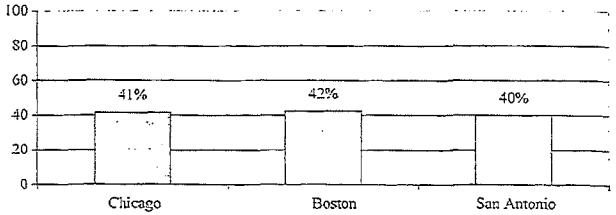

FIGURE 5.1. Percentage of employed primary caregivers by city

dilemma. Even relatively low wages could place at least some members of the family above the eligibility threshold for Medicaid. Two-parent families in which both parents work were at particularly high risk of losing eligibility.

The new State Children's Health Insurance Program (SCHIP) clearly addresses part of the problem but does not solve it. As we documented in Chapter 4, many eligible children remain uncovered, and the SCHIP program does not generally cover adults. Individuals without health insurance do not, of course, go without health care altogether because many federal and state programs and some local programs provide care to individuals without private coverage (Bauman and Herrick 2000). These programs, however, are still charity, and they often have restrictive eligibility requirements. They rarely provide all of the care individuals or families need, especially for chronic care or mental illness, nor do charitable sources provide the continuous and seamless care that the middle class enjoys and expects.

As our ethnographic interviews revealed, tenuous and weak ties to the labor force, episodic and discontinuous employment, and jobs in the service sector placed employment-based coverage out of the reach of all but a small fraction of our study families. Only a very small fraction of our respondents worked full-time. Figure 5.1 shows that in fact only about 40 percent of the respondents in the survey reported that they had worked at all for pay during the past week in any of the three cities. The ethnography made it clear that these survey-based figures included individuals who were working part-time as well as those who were only temporarily employed and who would lose their jobs the following week. Some of those who reported not working last week would find work the next week. In light of the volatility in the

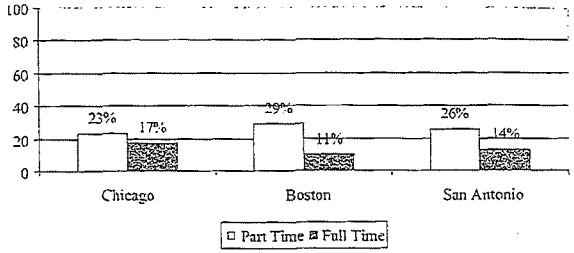

FIGURE 5.2. Type of employment for primary caregivers by city

employment status of this population, it is clear that snapshots of the sort we get from surveys tell an incomplete story and that the distinction between employed and unemployed is imprecise for the working poor. Many of the working poor have low incomes because they work only part-time, either voluntarily or because they do not have the option of working more hours. Among our respondents, part-time work was the only employment that most could find. Figure 5.2 presents information on the number of hours the respondent usually worked each week. Most respondents did not work at all, and in Figure 5.2 we differentiate between those who reported that they usually worked between one and thirty-nine hours per week and those who reported that they usually worked forty hours or more. It was up to the respondent, of course, to interpret what the term "usual" meant. The question did not refer to last week and could have been interpreted as how much one works in one's current job, one's last job, or even how much one would like to work.

However the respondents interpreted the question, the figure shows that the employment experiences of parents in the three cities were fairly similar. Less than 30 percent of the three samples reported that they usually worked between one and thirty-nine hours. An even lower proportion reported working full-time or more. Between approximately 10 percent and 17 percent of respondents reported that they worked forty or more hours. The fact that respondents reported slightly more part-time work and slightly less full-time work in Boston than in the two other cities may again reflect Massachusetts's more liberal welfare policies. Regardless of city, however, it is clear that regular

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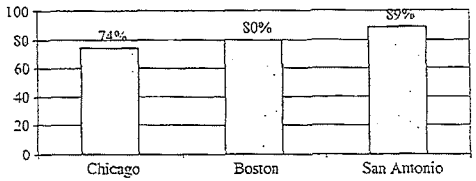

FIGURE 5.3. Percentage of primary caregivers employed in the services sector by city

employment was not the norm among the respondents in the survey. These statistics reveal low rates of employment but do not tell the whole story, which was one characterized by much instability and churning in and out of the labor force and between jobs. These statistics, in fact, probably overstate the real employment status of our respondents.

As these data illustrate, one of the core problems with employment-based health coverage for the working poor results from the fact that employers in the low-wage service sector frequently offer an employee only part-time work with variable hours and rarely offer health insurance. Given their low profit margins, employers in the service sector often cannot afford to offer coverage to their employees. Even outside the service sector, low-wage workers are far less likely than better-paid workers to have health insurance (Claxton et al. 2004; Collins et al. 2003).

Figure 5.3 shows that the vast majority of those respondents in the survey who worked did so in the service sector, which includes jobs in areas such as fast food, retail, general health, and maintenance. Some workers in this sector worked informally as housekeepers, child care workers, babysitters, volunteers, and community workers. Again, some city differences emerge from the survey. A larger percentage of workers in San Antonio, for example, were employed in services than in either Chicago or Boston. For the most part, however, the jobs our respondents held in each city were not very different. Data from the ethnography also revealed that the jobs that parents held were similar in all three cities and included domestic work, clerical work, child care, fast food and cafeteria work, and work in other service occupations and for temporary agencies. In each city, a handful of women found more stable employment, but they were the exception. One

San Antonio mother was a bank clerk and one Chicago mother worked for a management company. A few others held such jobs, but most did not.

Boston presents an interesting picture. As in Chicago and San Antonio, a substantial fraction of parents in Boston had been unemployed for a long period, if they had in fact ever worked. Most of the jobs our respondents in Boston held were similar to those held by our Chicago and San Antonio respondents. However, seven of the mothers in the Boston ethnographic sample reported jobs that seemed from their descriptions to promise real employment stability and security. However, upon closer examination of the circumstances of each of these cases, it was clear that the stability was only apparent and these cases illustrate why this slightly elevated tier of jobs did not offer any real long-term security. One mother had acquired the skills and contacts to obtain a full-time job as a receptionist at the time we first met her. However, we found out that she had worked at four different jobs in the preceding two years. Each job had been interrupted by a combination of family illness and child care problems that made it necessary for her to quit working. Like the mothers in clearly inferior jobs, she had no backup or reserve with which to weather the crises even once she had found a better job.

Another Boston mother worked between thirty and forty hours per week as a cell phone technician. However, her job provided no benefits, and she was vulnerable to the problems that any illness that she or her children might experience could cause. A third mother held a full-time job in a medical records office, but after a year and a half she still had no benefits and was also vulnerable to health crises. A fourth mother worked in a hospital kitchen. She had some health benefits, but her salary remained so low that she was dependent on both subsidized housing and food stamps.

Three other Boston mothers seemed to enjoy real job stability. One worked as a medical assistant at a job that provided family health benefits. The two others worked as a bank teller and for a major hotel chain. Two of these women had some college education, but what really seemed to make a difference was the fact that they shared housing with another person who provided full-time child care. Even for these women, however, employment stability could not be taken for granted. The hotel chain worker had begun working when her youngest child

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entered elementary school. The school offered an extended day care program that made it possible for her to work, and she had been working for a fairly long period. Unfortunately, when tourism in Boston took a downturn, she was laid off. When we were last in contact with her, she was living on unemployment insurance that would soon end, and her health insurance had been terminated.

The medical assistant was taking classes at a local community college and hoped to become a licensed registered nurse in a year or two. Her dream was to move to Florida, where, as she said, "there's a good community for the kids, where the rent is good, and where the pay is good, where they have lots of hospitals and they'll have opportunities for me." Completing her education and qualifying as a professional was clearly her route to self-sufficiency, but it was a route few mothers could make work. The bank teller, who was Latina and had an excellent command of both English and Spanish, received a promotion to customer service representative and was transferred to a new suburban branch. There, however, she was the only Hispanic and had serious difficulties with her supervisor, who criticized her language skills and even made reference to her ethnicity. The situation was clearly strained, and she received an unsatisfactory performance evaluation, which she refused to sign. As we shall see in the next chapter, for minority Americans the fact of race and ethnicity often affects their employment opportunities and experiences. After speaking to the personnel manager and a vice president at the bank, she was able to move back to her original branch, although she was afraid that even though her recent performance evaluations had been good, the bad performance evaluation she had received from the previous supervisor would hurt her chances for further promotions.

These women, even with their employment insecurities, were clearly the exception. We fairly quickly came to realize that even among those who claimed to be employed, many worked at jobs that were in reality informal and unstable. Many in fact really stretched the meaning of the term "job." The work they took provided low and unpredictable wages and no benefits. Many middle-class families routinely employ cleaning ladies and gardeners and pay them in cash. Neither the employer nor the employee pays Social Security or other taxes. Such jobs are quite common in our economy and were common among our ethnographic respondents. The fact that our respondents were so often unclear about

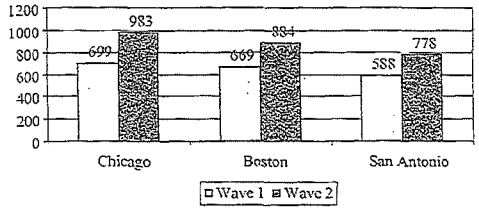

FIGURE 5.4. Average monthly income for working primary caregiver by city

their employment and insurance situations leads us to suspect that survey reports of employment and amount of work performed by those at the economic margin contain substantial misinformation. Such error again reflects the ambiguity and instability in the work lives of the working poor.

States, of course, differ in their labor market compositions, their wage rates, and other aspects of employment, and we wondered whether these differences might have an impact on the earnings of our study families. Figure 5.4 shows that in both waves of the survey total household earnings were higher in Chicago than in Boston and lowest in San Antonio. By the second wave of the survey, after welfare reform had forced some individuals to find jobs, average monthly earnings in San Antonio were less than $800 a month. An income of $800 a month translates into annual earnings of $9,600. In Chicago, where earnings were nearly $1,000 a month, average annual earnings still totaled only $12,000. In 2001, the federal poverty level for a single mother with two children was $14,269. Clearly, earnings at this level are too low to allow a family to become self-sufficient, and even slightly increased earnings place a working poor family at risk of losing the means-tested benefits that its members so desperately need.

These data then clearly illustrate the dilemma that low-wage families face. The earnings they receive from the jobs they can find leave them with no discretionary income with which to purchase expensive private health care coverage. Yet their desire to work and the requirements of welfare reform force them into jobs that may jeopardize their family's health care coverage. As we have noted, the national statistics on the number of Americans without health insurance are disturbing in and of themselves, but they cannot convey the complexity and urgency of

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the real-life situations that poor and working-class families face as a result of the instability of their medical care coverage and the resulting variability in their access to health care. A large body of research clearly documents the fact that the lack of health insurance reduces health care use by individuals and results in poorer health (Institute of Medicine 2002a). Poor health reduces one's productivity and long-term career opportunities. The lack of health insurance therefore has major long-term individual and social implications. Our interviews revealed that the instability in health coverage is both the result of instability in work and also one aspect of the work lives of working poor families that creates and perpetuates family instability. The stories we recount in this chapter reveal how elusive middle-class stability is for the poor, especially in terms of health care coverage.

Marginal workers, including many employed single mothers, have never enjoyed health care security for themselves or their children. Medicaid and SCHIP represent clear improvements that, at least in theory, address many of the health care financing problems of the working poor, at least for their children. However, the mothers in our study experienced the impact of several trends that during the last decade have changed the nature of the jobs available to them and have made employment even less stable. These trends have often left employed mothers with less access to health insurance coverage for themselves, and to some extent their children, than unemployed mothers. Single mothers, especially those with low levels of education, have historically had considerable difficulty in finding and keeping well-paid full-time employment. The demands of child care and employment often conflict, and much of the work available to young women is seasonal or unpredictable because of the volatility of the markets within which many service-sector employers operate.

Only a small proportion of the mothers in our ethnography remained employed for long periods in jobs with regular hours. For the most part, when mothers were employed, they held jobs that did not include even a rudimentary benefit package. Women and their children were not only ineligible for employer-assisted health insurance but also rarely entitled to the sick days or personal days that would allow them to retain their jobs when the mother or child became seriously ill. Finally, even when mothers found full-time employment in jobs that offered health coverage, they could rarely afford either the employee

contribution required or the co-payments that were required for office visits and prescriptions. Their access to dental care and eye care was often determined by their very limited access to some form of charitable or discounted service.

In exploring the work–health insurance nexus, or rather the lack of it, for our ethnographic families more closely, we begin with an analysis of their basic employment patterns and difficulties and illustrate the extent to which their experience is dominated by episodic and marginal jobs. We also examine the extent and nature of employer-provided benefit packages to which a service-sector worker might have access and illustrate the numerous reasons that they do not take advantage of such coverage even when it is offered. Finally, we explore the alternatives that low-income mothers often turn to when they or their children need medical care.

Employed or Not

An initial review of the most recent jobs held by the mothers in the ethnography provides insights into the survey findings of very low employment rates and reveals the difficulties that marginal workers face in finding and holding jobs. Our initial coding of the 155 ethnographic families (from all three cities) for which we had the most complete job information revealed that approximately one-third (56) were unemployed for a period of at least several months prior to our interviews (Lein et al. 2005). Of the remaining two-thirds, only about one-third (33 of 99) held a single, nearly full-time job. These jobs were predominantly in the service sector and included work in health services, food preparation and serving, domestic work, and sales. Even those mothers who worked close to full-time experienced some shift in hours worked, and few had access to affordable benefits. The handful of mothers with full-time employment and benefits that included at least some health care coverage held manufacturing jobs or jobs in public service. Only one mother in our San Antonio ethnographic sample received health care benefits that covered the entire family through work. Through diligence and hard work, this mother had advanced in the organization for which she worked and had finally arrived at her current position, but she continued to worry about what would happen to her family should her employer go out of business or were she to lose her job.

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The rest of the women in our sample pieced together multiple jobs, were often underemployed and worked only part-time involuntarily, and experienced frequent spells of unemployment. This work instability and unpredictability undermined any attempt they made to develop routines and to organize their daily lives, let alone gain skills and experience that would allow them to seek different kinds of work. Some of our mothers worked continuously but were constantly underemployed, and we came to realize that given the nature of marginal work, underemployment is in many ways far worse than unemployment, especially as it often affects eligibility for public programs. These underemployed women earned poverty-level wages but they were, particularly in Texas, ineligible for welfare assistance or public health insurance.

The work lives of the families we interviewed were unstable in all three cities, and a parent's employment affected Medicaid eligibility in each. The higher eligibility ceiling for Medicaid in Illinois and Massachusetts compared with Texas meant that more mothers and children remained eligible while mothers were employed in those two cities. In all three cities, however, mothers still lost their eligibility before their children did, and in all three cities jobs and medical insurance were jeopardized by the demands of the Medicaid application and recertification process. Sarah, the young African American mother with whose story we began the chapter, had to struggle constantly with the unpredictability that work imposed on her life and on her access to health care.

More of Our Interactions with Sarah

Sarah's situation was typical of that of the other families in our study and illustrates the extent of discontinuity in her employment and her family's health care coverage. As in the majority of the other cases, the combination of the unpredictability of her employment and difficulties with the recertification process resulted in interruptions in coverage. Sarah's case, however, introduced a new complication that made her situation even more difficult. Sarah was involved in an abusive relationship that finally made it necessary for her to move in order to escape her abusive partner. As a result of the move, both her work and the family's Medicaid coverage were again interrupted.

When Sarah's three older children were infants, the family was on TANF and Medicaid, although her coverage was not continuous.

TABLE 5.1. *Time Line of Sarah's Employment and Health History in 2000*

The Year 2000	1st Quarter	2nd Quarter	3rd Quarter	4th Quarter
Job	Working at day care center	Meat-packing job	Clerical work	Clerical work at child care facility
Health Insurance – Self	Medicaid	None	None	None
Health Insurance – Children	Medicaid	None	None	Medicaid
Health Problems	Child with respiratory ailment	Child with respiratory ailment	Child with respiratory ailment; daughter has burn	Child with respiratory ailment; son develops small tumor

Sarah remained with her children's father through this period, and the fact that he was in the household and had earnings affected the family's eligibility because the family income criteria are less generous for older children and the spouse's income, even if low, adds to the household total. Just before Thanksgiving in 1999, the relationship deteriorated and she called the police after a fight that was provoked by his treatment of her children. The initial argument escalated into a serious fight and he beat her. When the police arrived, they arrested him and he was jailed, after which he was placed on parole. Around Christmas, he called her, but when she hung up on him he came to the house in a rage and beat her again. As a result, his probation was revoked and he went back to jail.

The first jail sentence and period of parole sent the family into a very chaotic year. In order to attempt to make sense of the very complex narrative of the events of that year, we present it in Table 5.1 as a time line that summarizes Sarah's employment status, her health insurance status, the health insurance coverage of her children, and their health problems, as she related them. While working in turn at the day care center and the clerical jobs, Sarah was able to negotiate for the time she needed to recertify her children for Medicaid. She herself was not eligible for Medicaid while she was working, but none of the jobs she held offered health insurance so she went without any coverage. During her time at the meat-packing plant,

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however, the entire family was dropped from Medicaid because Sarah missed appointments for recertification. She could not take time off work because of the loss of pay and the risk that she would be fired for excessive absences. As the direct consequence of policies that are designed to encourage mothers toward employment, the mothers themselves often face trade-offs between employment and health insurance.

The narratives provided by our respondents were complicated and, as in Sarah's case, they did not always make sense and did not always offer clear sequences of events or plausible justifications or explanations for what happened. The reasons for the frequent job transitions, for example, were not always obvious, nor might they have been entirely clear to the respondents themselves. Sarah told us, for example, that she left the job in the day care center for the better pay and more regular hours at the meat-packing plant. However, she then left that job for the clerical job because she needed more flexibility in order to meet the demands of the welfare system and have the greater freedom to apply for health insurance and child care benefits for her children. Without a child care subsidy, and with her aunt unable to care for her children full-time, Sarah changed jobs yet again to work at a day care center where her children could accompany her. She was able to negotiate enough flexibility in that job to allow her to make the necessary appointments to regain Medicaid for her children.

During the following year, her children's father, in jail for attacking her, threatened to find her and hurt her when he was released. To escape from him, in 2001, just as we ended our data collection, she moved to a different city and started her life over, including new attempts to find employment and obtain health insurance. Sarah spent a great deal of time and effort to obtain and maintain Medicaid eligibility for her children, and these struggles interacted with the difficulties of finding and keeping a job as well as supervision and care of her children. Her case also illustrates how few options adults have for health care insurance for themselves. Both the ethnographic data and the survey data show that a much higher proportion of children than parents have health insurance. Gloria, whose story follows, illustrates the difficulties faced by caregivers who cannot find health coverage for themselves, even when they can keep their children insured.

TABLE 5.2. *Time Line of Gloria's Employment and Health History, 1999–2001*

	1999	2000	2001
Jobs	Works at hamburger restaurant; cleans motel rooms; works at family restaurant	Works at hamburger restaurant	Works at family restaurant
Health Problems	Falls at work/breaks arms; children face series of illnesses; takes children out of day care	Loses child care subsidy	Shares child care with her partner

Gloria

The situation of another young non-Hispanic white mother further illustrates the complex tie between unstable work, an unstable family life, and unstable health care coverage even for nonminority families. It also illustrates the hopelessness of Gloria's attempt to obtain health care for herself. While Gloria was trying hard to make sure her children had health insurance, she simply did without it herself. As a result, she was forced to manage her own health care differently from that of her children. Gloria was twenty-two years old when we met her. She had a three-year-old girl and two-year-old twin boys. The girl and the twins had different fathers. The father of the twins was in another relationship and had not visited his children in over a year. The older child's father, however, was still involved and visited the little girl and made occasional financial contributions to the family. All three children had been diagnosed with asthma, and one of the twins was developmentally delayed. Because they were so young, the children had been covered by Medicaid almost continuously since their births, except for a few lapses when the recredentialing process did not go smoothly. Gloria never had health insurance. As a result, and as we will explain in greater detail, when she suffered a work-related accident that required medical care, she had to go to court to try to get payment from her employer in order to cover the costs of her treatment.

As in Sarah's case, Gloria's life is complicated and her account sometimes rambling, so we summarize the highlights in the three-year time line in Table 5.2. Gloria left high school after the tenth grade. She worked in fast food restaurants for several years and was in one of those

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jobs when her first child was born. However, because of a combination of health problems and child care problems, she was unable to hold on to any one job for long and moved from one service-sector job to another, experiencing ongoing intermittent unemployment.

Each work transition was marked by some problem related, at least in part, to difficulties in obtaining health care or arranging for child care. In 1999, Gloria, as usual, had no health insurance and suffered the job-related injury we mentioned earlier. She was then unable to continue at the job on which she was injured and searched for a new job at the same time she was involved in legal action that she hoped would result in a court judgment forcing her employer to pay for her work-related medical expenses. Before she was fully recovered, she took a job cleaning motel rooms. She was able to accept the job offer because at that time she qualified for and was able to find subsidized child care. Her employment problems and the family's health problems continued, however. All three children suffered a series of infections, and Gloria lost the cleaning job because of her absences from work that resulted from the children's health problems. She then spent a few months unemployed.

Determined to work, Gloria found another fast food job and worked there until she felt that the subsidized day care program that she had been using was not taking adequate care of her children, particularly when they were ill. Perhaps because they were not getting adequate care, or because of the other stresses in their lives, the children's health was deteriorating, and when their chronic health problems became serious, Gloria was unable to send them to regular child care. As a result, Gloria lost her child care subsidy. Because finding and paying for child care for three children herself was impossible, Gloria was forced to reconsider her strategies. In her next job, the fast food job she had when we last interviewed her, she worked a late shift so that she could care for the children during the day. While she worked, her new partner stayed home with the children.

In spite of all her difficulties finding and keeping a job, Gloria believed that work was important and that it was much better for her children for her to work than for the family to be on welfare. Throughout the period during which we were in contact with her, she remained diligent in her attempts to stay employed. Despite her determination, however, health and other family problems overcame her best efforts,

and even though she intensely disliked being on welfare, occasionally it could not be avoided. Even the need to apply for Medicaid was demeaning to her. "It [dealing with Medicaid] is difficult because they never trust you and every time you go you have to prove you don't have a car, what your income is, and that you don't have any other bank accounts." Gloria was typical of mothers who found themselves facing a number of bureaucratic obstacles in their search for health care even though it was self-evident that publicly supported health insurance was their only possible recourse.

Gloria's access to health care was reduced because she worked. She was ineligible for Medicaid, but her job offered no health benefits. Her children were eligible for Medicaid, but the work required to keep them continuously covered put her jobs at risk. Furthermore, as her children get older, their eligibility for Medicaid will decline, again especially if Gloria continues to work. Indeed, if Gloria, or any of the other women in our study, were to actually succeed in increasing their incomes, they would probably end up worse off from a health insurance standpoint because of the loss of Medicaid or SCHIP. During one interview, Gloria told us that she intended to apply for the low-payment reduced cost and debt management program we mentioned earlier that is intended for people who are not eligible for Medicaid. Gloria realized that, working or not, she had to accept some help; however, the reduced payment program is not an entitlement program. Its ability to help is limited by its funds, and it was unclear whether Gloria succeeded in receiving that service. With three children who are chronically ill, she continued to combine work with ongoing recertification for Medicaid for her children. Gloria's own income kept her above any eligibility for Medicaid for herself, and her other options were limited.

Gloria's determination to be a responsible parent and her concern with health care, with work, and with child care were motivated by her desire to be a better parent than her own mother. Like almost all of the other women we talked with in the course of our study, Gloria's core identity was that of mother, and all of her other roles and activities were defined by and supported that core identity. Gloria was one of thirteen children and as she explained, "There were just too many of us....I want to spend more quality time with them [her own children]....I want to let them know that they can talk to me instead of learning everything on the street like I did." On top of her

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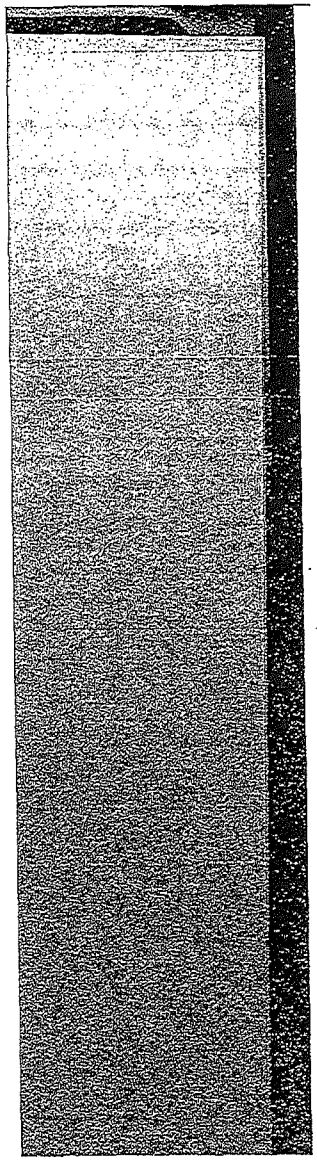

struggles to earn a living, to maintain health coverage at least for her children, and to locate responsible child care, Gloria also worried that she could not spend the time necessary with her children to do a good job raising them. Like many of the struggling mothers we interviewed, Gloria's parental role was undermined by the characteristics of the service-sector jobs she held.

The Service-Sector Trap

The problems that our ethnographic families experienced are becoming more common in general because as in our study cities manufacturing jobs are being displaced by low-wage service-sector jobs in the nation as a whole (Bivens, Scott, and Weller 2003; Bluestone and Harrison 1988; Bureau of Labor Statistics 2004a; Bureau of Labor Statistics 2004b; Congressional Budget Office 2004; Didrickson 1997; Thompson 1999). Workers with low levels of education and experience, and the women we interviewed in particular, are very unlikely to find unionized manufacturing jobs that include guarantees of hours, wages, and benefits. Like Gloria, they are more likely to find work in food services, health care, and retail sales in which union organization, especially in right-to-work states such as Texas, has been unsuccessful.

Except for young workers who hold service jobs while they finish their education or for temporary purposes, few service-sector jobs are part of a career ladder. The work histories of the older mothers in our sample illustrate how one service job follows another, each with similarly low wages and no access to health insurance. Thus, although the relatively short-term "transition" benefits are often available to families as they depart welfare, they only delay the almost inevitable arrival of a time when at least some members of the household will lose health insurance coverage when a parent becomes a wage earner. One of the older mothers in the ethnographic study, Dora, had been in and out of the labor force since 1989, when she began her work life in a jewelry store after high school. Dora stopped working shortly after her second child was born, so that she could stay home to care for her two children. At the time, she was still married, but when she separated from her husband in 1994, she was forced to take a job at a fast food restaurant that she found through a referral from friends. She

worked at that job for three months and then switched to a job at a buffet restaurant, where she worked for another nine months. Neither job offered benefits, and both had rotating shifts.

Dora received TANF for several years after the birth of her second child until she resumed restaurant work as a waitress for a year. In a rather short period, she moved from the waitress job to a bookstore job and then to a job at a grocery store. None of these job transitions resulted in a substantial improvement in Dora's situation. In none of her jobs was she employed full-time or offered benefits. When the study ended, Dora had left the grocery store job because her child care arrangements, which were always a bit irregular, fell through. When we were last in contact with her, she was in the process of rearranging child care and trying to get back into the labor market. Like so many of our mothers who had only a high school education and few job skills, the low-wage service sector provided no access to improved wages, stability, or skills. At various points, her children's medical coverage lapsed, and Dora herself was usually without health insurance. Workers in this sector have very little hope of ever obtaining health care coverage for themselves or their children through work.

Unpredictable Schedules

These cases illustrate the extent of instability in our respondents' job histories. Jobs in the low-wage service sector require few skills and are easy to get and easy to lose. Most of our respondents had held many such jobs, and their narratives made it clear that one of the characteristics of such jobs that undermines stability is the worker's lack of control over his or her work schedule. Our respondents had little control over their schedules, the number of hours they worked, their earnings, or any other aspects of their jobs. Our interviews revealed just how unpredictable the daily schedules of low-wage workers can be and how that unpredictability undermines their attempts to get ahead. This instability of work itself is a very poorly understood aspect of low-wage employment that results in what might be seen as irresponsible behavior or a lack of initiative on the part of workers themselves.

Work schedules that change from week to week make it almost impossible to enroll in training programs or to piece together additional

jobs that might allow a poorly educated, low-income parent to develop work-related skills or to increase his or her earnings. Even if a mother has free hours one week, she may have to work during those times the next week. That lack of predictability affects the whole family and interacts with problems maintaining health care coverage. A less than full-time job that offers no benefits, sick leave, or vacation days can become full-time in its effects. The result is a catch-22 in which low-wage work provides no valuable job skills and keeps a worker from increasing his or her human capital through education or from earning extra income through additional work. These families find that their health care benefits are often as unstable as their jobs. Although children may regain access to Medicaid during periods of parental unemployment, such coverage requires considerable time and energy to maintain and rarely extends to the unemployed adults in the family.

Work by a team of researchers in Chicago documents the ways in which the growing number of service-sector jobs in which our mothers are likely to work are structured to prevent those who work in them from gaining the status of full-time employees or becoming self-sufficient (Lambert, Waxman, and Haley-Lock 2002). Like our ethnographic data, this research shows that although such jobs may have set hourly wage rates, the number and scheduling of hours worked vary from week to week and are not under the control of the employee. As a consequence, one's income varies, sometimes dramatically, and scheduling, budgeting, and saving are difficult. One spends virtually all of what one earns for daily needs, and any meager savings one manages to put away can be easily wiped out by an emergency or during a period of underemployment or unemployment.

Jobs in health services, fast food, and retail often schedule their employees for one week at a time. Although individuals who hold these jobs may be classified as full-time workers, they seldom work a full thirty-five to forty hours a week and do not receive the predictable income of true full-time workers. Unpredictable schedules make it almost impossible to enroll in training programs or to piece together additional jobs. The result is a situation in which low-wage work provides little stability, few valuable job skills, and keeps a woman from acquiring additional human capital through education or additional income through additional work.

No Job Security

Many of the jobs the mothers in our ethnographic sample worked were short-term. In many cases, the work was seasonal or the jobs were dependent on the high end of a business cycle. Often the work was sufficiently physically demanding that most workers could only tolerate the job for a limited amount of time. Again, however, the common denominator was that workers in these jobs had little security and were unable to negotiate wage levels or the hours they worked. In these environments, negotiating for benefits was hardly an option. Much of this powerlessness came from the nature of the jobs and the fact that they were relatively easy to get and easy to lose. Jobs in agriculture, the tourist industry, public schools, and other work domains are often seasonal, and low-wage workers are often laid off or offered only short-term contracts. The mothers in our sample were clearly part of the growing sector of contingent employees who are hired when extra help is needed and let go when that need ends.

The instability at work and low wages, along with the lack of benefits, result in and interact with other uncertainties in families' lives in ways that make it even more difficult for a parent to keep a job. A parent's own illness or injury, a child's sickness or disability, the requirements of the welfare system for frequent recertification, and a host of other problems interfered with many mothers' ability to remain employed. Most of the marginal jobs in which our mothers worked did not provide sick days or personal days, and very frequently a short absence because of illness or some other family emergency meant termination.

A Last Visit with Sarah

Sarah, who held the twenty-hour "full-time" job described earlier, was ineligible for benefits on that job because of its hourly nature. In order to make ends meet, she also took care of her friend's child for thirteen hours a week. Because she had no alternative, she turned to the public health care system for her children but remained uninsured herself. Her wages placed her well above the extremely low income

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threshold for adult women. Because one of her children had respiratory problems, Sarah had applied for SSI for the child, but that application was denied. Meanwhile, she had no insurance for herself, and her struggles to maintain it for her children continued.

Sarah's case illustrates many of the health insurance problems that our mothers faced once they entered the labor force. In general, the jobs they were able to find did not offer health insurance. As we noted in Chapter 1, employment-based health insurance coverage expanded rapidly after the Second World War but seems to have reached a saturation point. Even jobs that pay far more than those our respondents qualified for no longer offer the low-cost health insurance they once provided employees (Claxton et al. 2004; Collins et al. 2003). The costs of health care and health care coverage have skyrocketed. Employers have no choice but to pass a larger fraction of the cost on to their employees or to drop health insurance altogether. There is little reason to believe that the situation will become anything but worse for low-wage workers as employers continue to limit coverage or pass more of the cost on to employees and as the federal and state budgets for health care are curtailed by austerity measures.

Conclusion: Work Is Not Enough

One aspect of the lives of the poor that became obvious to us during our study and that we will explore in greater depth in the next chapter was the extent to which the hopelessness of the reality of their situations came to define their expectations. Few mothers had adequate incomes or any real chance of ever becoming self-sufficient, and almost none had continuous health insurance. Self-sufficiency and continuous household health care coverage were simply outside of the realities of their lives. Although these women wished to work and to be as responsible as they could in their roles as parents, they held few expectations that work would greatly improve their lot. In fact, the possibility of health insurance through employment was so irrelevant to our respondents that they rarely mentioned it as a factor in deciding which jobs they would take. Their decisions about which job to accept or whether to work at all were based on more rudimentary considerations such as which job was least onerous in terms of hours, child care requirements, and location. Women in this situation quickly become realists, and, as one mother candidly told us,

it is the nature of the work available to women like her that explains why so many mothers cycle off and on welfare.

> Because when they get off welfare, they get a job at McDonald's because they have no education. As soon as they get a job, they lose their food stamps, they lose their Medicaid, and they have to start paying rent, insurance. They can't afford that. So they work for two months, then get off and go back on welfare. You have a year. Then you work a month or two, then get off and go back on welfare. You have another year. So it's almost the way they've learned to beat the system. Even now, at the program, you're supposed to work.

In the few cases where employer-sponsored health insurance was an option, mothers still had problems taking advantage of it. In a few cases, mothers were offered health insurance but the employee contribution demanded of them was too large a part of their income and they could not afford it. Employee contributions to health insurance act as a regressive tax in that the premiums represent a larger share of income for low-wage workers, and required employee contributions increase when other family members are included on the plan. For mothers who cannot afford their own health insurance, the cost of the contribution they must make for coverage of their children is almost always prohibitive. Only two of our ethnographic mothers were able to insure their entire household through employment-based plans even for short periods of time.

Co-payments and deductibles were another aspect of most employer-assisted health care plans that presented major barriers to low-income mothers. Even in those rare situations in which mothers could obtain private health insurance, they often found themselves rationing their own use of health care services because of the co-payments and the deductibles that were required. Unfortunately, neither Medicaid nor private insurance cover all medical expenses. The mothers in our study were often left with sizable expenditures even when they had health care coverage, as we learned from their stories concerning difficulties obtaining dental or eye care and of their inability to pay for all of the over-the-counter and prescription drugs and other materials recommended or prescribed by their physicians.

A Growing Problem for Working Families

We end this chapter by noting that although our study focused on the health insurance difficulties of the poor, the crisis in health care

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coverage is no longer confined to the bottom of the income distribution. Increasingly, instability in health care coverage, like instability in employment, is moving up the job hierarchy and affecting more working and middle-class families. If there is any hope for a change in the system, it arises from the fact that the poor are no longer the only victims. President Johnson's War on Poverty was in most respects a historical fluke, and we are unlikely to see major political initiatives to improve the lot of the poor in the near future. High rates of medical inflation and the growing vulnerability of the middle class, however, could serve as a major engine for change in the system as a whole. As we noted earlier, the major cause of bankruptcy in America today is crushing medical debt (Jacoby, Sullivan, and Warren 2000; Jacoby, Sullivan, and Warren 2001; Sullivan, Warren, and Westbrook 2000). As employers drop expensive health insurance plans or shift a larger portion of the cost of health insurance to employees, as more middle-class workers find themselves redefined as independent contractors or contingent workers, and as retirees find that the promises of lifelong health care that were made to them during their working lives are not honored, more middle-class Americans will experience the health care financing uncertainties that have historically plagued the poor. Our families then are the canaries in the mine that signal that we may all soon have something serious to worry about.

The working poor have never enjoyed true job security, and in many ways they have served as the bellwether for a new trend toward contingent and contract employment in which there is no long-term employer/employee contract or a strong sense of mutual loyalty and responsibility. The fact that the post–World War II benefit package, which included full family coverage for unionized and blue-collar workers, is eroding in value may serve as the motivation for more basic structural reform of the health care financing system. Many employers are beginning to fill some positions by contracting with secondary agencies or using temporary workers (Barker and Christensen 1998). Although many workers prefer the flexibility of such contingent employment and some contingent jobs pay relatively high wages, some of these new jobs share many of the characteristics of the jobs in which the mothers in the ethnography worked on and off. The essence of this new contingent arrangement is that the worker is not a true employee of the firm for which she works on a short-term basis. Unlike permanent

employees, they are not entitled to any benefits the employer may offer, nor do they have any long-term job security.

Globalization and market uncertainty create the need for a highly flexible labor force that allows firms to react quickly to changing situations. Contingent employment, outsourcing, and just-in-time inventorying create employment environments in which the tie between employer and employee becomes looser and less paternalistic. Although certain high-productivity workers must be kept on the payroll even in slow times to ensure that they will be available in good times, production line workers, office staff, and maintenance workers are only needed on a contingent basis. Increasingly, rather than hiring one's own staff to fill maintenance, administrative, or production slots, the services these employees provide are purchased from some third party or independent contractor. By contracting out, the firm is no longer responsible for providing benefits.

In the end, our analysis of the survey data and a close examination of our ethnographic data made it clear that the employment–health insurance nexus that has served the middle class so well does not exist for those at the economic margin. Low-wage jobs are defined by sectors of the economy in which profit margins are low and in which employers face stiff competition that forces them to keep wages as low as possible. For workers in this part of the service sector, upward mobility, self-sufficiency, and adequate health care coverage remain elusive goals. Although they would have clearly preferred employer-sponsored health insurance over public coverage, our ethnographic families needed the income more than the coverage, or rather they needed both but simply could not make the income sacrifice. The situation of these families clearly revealed the inherent dilemma of an employment-based health coverage system in which jobs that pay low wages also provide no or only prohibitively expensive benefits.

In closing, we must reiterate that in discussions of poverty and the lack of health insurance race and ethnicity are unavoidable topics. One's position in the labor market and one's risk of poverty are influenced by race and ethnicity as well as by one's immigration status (Lee and Angel 2002). Massachusetts, Illinois, and Texas are among the eight states with the largest minority and noncitizen populations, groups that are disproportionately poor and politically powerless. Approximately 17 percent of noncitizens in Massachusetts and Illinois

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and 34 percent in Texas live in poverty (Zimmerman and Tumlin 1999). Even legal immigrants are ineligible for most public programs for a period of five years after they arrive. States differ in the services they provide to immigrants. Texas has one of the least generous insurance programs for immigrant parents and children in the nation (Capps 2001). In contrast, Massachusetts provides generous health coverage in addition to other social services for immigrants and is among the states with the highest rate of health care coverage for immigrant children in the nation (Tumlin, Zimmermann, and Ost 1999). Illinois falls somewhere between the two (Zimmerman and Tumlin 1999).

Although all the families in our ethnographic sample were selected to be potentially eligible for welfare and therefore were legal residents, Mexican-origin families occasionally talked about the impact of attitudes toward immigration and the enforcement of immigration laws on their own experiences. We quickly came to understand that immigration and citizenship were part of a complex group identity that affected individuals' experience of their minority status and that fed into their experience of powerlessness in the face of complex welfare bureaucracies. In Chapter 6, we examine how race and ethnicity influence one's experience of poverty and powerlessness and how one's identity is determined by one's interaction with the welfare system and the larger bureaucracy.

6

Confronting the System

Minority Group Identity and Powerlessness

The plight of low-income families like those in our study remains invisible and often incomprehensible to most middle-class white Americans. The poor, and particularly the minority poor, live in their own sections of town that most outsiders neither visit nor understand particularly well. What the average citizen knows about the poor is what he or she sees and hears on the evening news, gathers from the Internet, or reads in newspapers and magazines. Much of that information is negative and focuses on crime, family disruption, welfare dependence, and any number of other social pathologies. The fact that the waitresses, the busboys, the nurse's assistants, and the other service personnel that one encounters on a daily basis are so often black or speak Spanish among themselves only hints at the complex world that exists apart from America's richer neighborhoods and shopping areas. Although these low-wage workers are crucial to maintaining the high quality of life Americans enjoy, at the end of the day they return to their own neighborhoods and have little to do with the people they serve. They receive little thanks or appreciation for their efforts, and they receive even less money. They remain apart and outside the mainstream of middle-class American life.

The fact that poverty is concentrated in specific neighborhoods and among families of color continues to have serious implications for the residents of those neighborhoods, as well as for the public support of social service programs and general perceptions of welfare (Gilens 1999; Kain and Quigley 1972; Quadagno 1988; Wilson 1987). As we

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situations just give up? What we observed was that most struggle on because they have no choice and, most importantly perhaps, because they have children for whom they feel a deep parental responsibility. A few, as we will see, even seemed to develop some sense of control, but many lives were clearly blighted by the demoralization that is an inevitable result of a stigmatized identity and the inability to control important aspects of life. We came to realize that the bureaucracies with which the poor must interact in order to survive are structured in such a way as to increase rather than reduce the number of obstacles they must overcome and to increase their sense of powerlessness and their demoralization.

Despite the fact that these families had few resources and had to deal with often intransigent bureaucracies, they also developed effective survival strategies with which to compensate for their absence of economic or social influence. As we have seen in previous chapters, these strategies were centered on a constant effort to gain some control over their lives, particularly in terms of the welfare of their children. When it was successful, their perseverance paid off in terms of the enhanced cohesion and strength of their families, their success in providing for their children, and their ability to negotiate and successfully employ a complex organizational environment. They learned to combine the services of formal governmental institutions to obtain TANF, food stamps, and Medicaid to obtain the basics of daily life, and more informal nongovernmental organizations, such as churches, food pantries, and other charitable organizations, for more episodic assistance.

It is clearly important for us to recognize the effectiveness that many families displayed in these efforts and also to recognize the real courage of their efforts. However, they found themselves in situations in which a large fraction, if not the majority, of their time and energy had to be devoted to obtaining the real basics of daily life. Unfortunately, their attempts to keep their households intact and their children healthy and supervised were not always successful. Most families in our sample were minorities, and most were attempting these challenging tasks in neighborhoods beset with crime, drugs, and general social disorganization, problems that interact with race and ethnicity to create low levels of economic opportunity (Wilson 1987). The fact that so much of their time had to be devoted to basics meant that little was left to

devote to educational programs or efforts to enhance job skills. The result was often a trap in which the lack of opportunity for social mobility or economic advancement fed back into a general community sense of demoralization.

In our interviews, we heard from unique individuals with different temperaments and different capacities for dealing with the difficulties in their lives. Like the majority of our sample, however, they share the reality of their minority-group status. As we have noted, few of our respondents overtly attributed their circumstances to the fact of their race or ethnicity. Of course, we did not probe directly for their conceptions of how their race or ethnicity affected their lives. Our conversations were more general and focused on daily routines, interactions with the welfare bureaucracy, and daily hassles. In this context, few of our respondents talked much about race or ethnicity at all. Some even rejected a racial or ethnic attribution for their problems. As one young African American mother of two boys told us, "I consider myself a person. I am a human being. I don't consider myself no African American or black or nothing like that. I am a person, period." This young mother told us that she did not talk to her children about race because she did not want them to focus on their color.

Despite the fact that this young mother did not want to talk about race, like most of our other study families she and her sons lived in a world defined by their racial and ethnic identity and largely distinct and separate from that of middle-class white America. What we found was that rather than defining themselves as racial or ethnic group members, the consciousness of minority-group status was confounded with aspects of social class powerlessness, and our respondents articulated the reality of their lives more in terms of powerlessness in the face of their poverty and the impenetrable and confusing bureaucracies that they were forced to rely on rather than overtly in terms of race or ethnicity. Although the stories we have already presented clearly demonstrate the powerlessness and lack of control that our families experienced, in this chapter we present several more cases to focus a clearer light on how race and Hispanic ethnicity are experienced in real-life contexts.

Yvonne

We met Yvonne, a thirty-year-old Mexican American mother of five, shortly after she had moved into The Courts. The housing project

consisted almost entirely of Mexican-origin families. Yvonne's friends and neighbors were all Mexican, and the neighborhood truly felt like a Mexican community. Like much project housing, the building in which Yvonne and her family lived was not in good shape. To get to the apartment, the interviewer had to climb a damp, grimy, and littered stairwell. The Courts dominated the neighborhood, and because it was spread out over a large area it created a considerable zone with few businesses and limited public transportation.

Our first interview took place on a hot summer day, and the window air-conditioning unit in one room could not keep the apartment cool. In addition to Yvonne, the family consisted of a daughter age three, four sons, ages five, seven, eleven, and fourteen, and Yvonne's new partner, who was not the father of any of her five children. His children were also living in the apartment, as was one of Yvonne's nieces and her baby. Occasionally a nephew who split his time between Yvonne's apartment and his mother's house also stayed with the family. With so many people, the apartment was crowded and Yvonne was challenged to keep order and to keep up basic maintenance. Such overcrowding is a major problem for many poor families, especially for Mexican Americans, who have high fertility rates and large extended families. Lacking resources or a safety net, the poor must look to relatives and friends as a last resort in dealing with problems. The traditional stereotype of large extended Mexican families living in crowded dwelling units by choice may, in fact, represent less a cultural preference and more simple necessity. Yvonne's acceptance of so many relatives represents her contribution to a mutual support network on which she may at some point be forced to rely.

Although we deliberately oversampled families with a disabled member, many of the families in our study who were not members of this oversample were caring for someone with a physical or mental handicap. The fact that blacks and Hispanics are at elevated risk of poverty and its health risks means that many families must care for family members with serious disabilities, and they must do so in difficult and trying circumstances. Yvonne's oldest son was disabled and mentally retarded. He attended a special eighth-grade program at the local public school because he read at the first-grade level. There were few other programs available to him, and caring for him took a great deal of time because he needed assistance in dressing and other

daily activities. Because of his severe disability the boy was eligible for supplemental security income (SSI), and the family received a monthly stipend. Supplemental security income automatically qualifies one for Medicaid, so at least this son was continuously covered for his medical care.

Yvonne had always lived in the barrio, and she grew up in a large, strife-ridden family. Her mother and father had four daughters together, but they separated while Yvonne was still a baby, and each had more children with other partners. With so many children, they could do little for any of them, and their lives embodied the stereotype of uncontrolled fertility that is so often attributed to minority individuals. Yvonne's mother had been diagnosed with AIDS and lived with Yvonne's sister. When we met Yvonne, she was dealing with the first of several health problems of which we became aware. Like most of our sample, she had no health insurance or any hope of ever acquiring employer coverage. She had been on and off Medicaid over the previous several years, but Medicaid did not always cover her prescribed treatments.

At the time of our interviews, Yvonne was suffering from rash-like bumps that itched unbearably and that were eventually diagnosed as flea bites to which she was allergic. She also suffered from the long-term effects of a childhood spinal injury that made it hard for her to meet the demands of her grocery store job and that required narcotic drugs to manage the pain. A few months after we met her, she and four of the five children developed a strep infection, and Yvonne lost several days of work because she had to remain home to recuperate and care for the children. Like many of the mothers we met, Yvonne's residence in a segregated and resource-poor neighborhood with only limited access to transportation seriously restricted her employment opportunities. With few other employment opportunities, Yvonne, like many other mothers in such segregated neighborhoods, often took jobs in the informal economy. Both African American and Mexican American mothers often worked at informal jobs where they were paid in cash and had no benefits and no security.

Over the eighteen-month period that we worked with Yvonne, she held four different jobs. None offered much income or stability, and none helped Yvonne feel good about herself. The first job was at a cafe, where she was paid cash by her employer, who did not pay Social

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Security taxes for his employees. The long-term consequences of such informal work are, of course, serious. Not only does one not earn enough to save for the future, but also because one pays no Social Security taxes one can easily fail to make the required ten years of contributions necessary to receive benefits. Even if Yvonne were to qualify, however, the small size of her contributions would entitle her only to the lowest stipend. Although we did not include undocumented workers in our study, those individuals are even more vulnerable to employer exploitation than citizens. Even for citizens, however, the fact of being Mexican with little education and few resources increases one's vulnerability in the job market.

The informal nature of her job caused other problems for Yvonne. At the time, she was in a special housing program that required that she find work within three months. Because the job was informal, the employer would not write a letter to the housing authority documenting her employment, so the job could not meet the requirements of the housing program. Faced with the possibility of eviction, Yvonne quit the cafe job and took a job in food service, but she quit that second job within the week. That job began at 6 A.M., and there was no public transportation running at that hour. Taking a cab was too expensive given the job's low wages, so Yvonne took a third job. For one month, she worked as a seasonal cashier at a local store, but that temporary position soon ended. Within a month, she took a fourth position, this time at the local grocery store. That job was typical of many of the service-sector jobs our respondents found. In most restaurants, construction sites, hotels and motels, and other service industries in the Southwest and increasingly in other parts of the country, cleaning and service staffs are largely Mexican and Mexican American, as are almost all of those working as agricultural labor (Capps, Fix, and Passel 2003; Kazis and Miller 2001; Taylor, Martin, and Fix 1997). None of Yvonne's four jobs provided enough work or income for her to support her family.

Throughout this period of the study, the family was on TANF, although the amounts varied considerably, adding to the ongoing uncertainty of Yvonne's life. Yvonne was penalized during one of her job searches because she had not been able to submit the fifteen job applications in one week that were required. In a limited local formal economy, typical of many depressed ethnic-minority communities, it is

difficult to locate potential employers, and the travel time to apply outside the community makes it difficult to submit numerous applications in a week. On another occasion, Yvonne was penalized because one of her children was late for a required physical examination. She told us that she had made the appointment, but her doctor was backed up for several months and could not see the child within the TANF-imposed deadline.

Yvonne was still trying to continue her education and had only two exams left to earn her GED. It was clear that one of her defenses against demoralization was a strong belief in education and the hope that with education her children would escape poverty. As she told us,

> I stress education to kids so much, and I would love, I swear, to get a college education for myself to do what I've always wanted to do, to get my college education, get my career. . . . I always tell people it wasn't that I was stupid and I couldn't go to school. . . . I mean most of the time I didn't even go to school because my mother never came home and I had to stay home with the other little kids at home, you know! I flunked the seventh grade.

When the study ended, Yvonne and her family were struggling to get by, but it was clear to us that their precarious situation would probably never improve because of the interaction of so many negative factors. The family was still trapped in a resource-poor neighborhood with few local job opportunities. Yvonne continued to juggle multiple and demanding responsibilities for her immediate family and for a much larger network, responsibilities that quickly drained off whatever resources she was able to accumulate. Despite it all, however, she was continuing her attempts to educate herself and her children. We left the family with the hope that Yvonne will see her children succeed and her own efforts on their behalf rewarded. It was clear, however, that the fact that she was Mexican placed her at a distinct disadvantage in terms of access to the means of achieving that success.

Sonia

Although Sonia faced a series of responsibilities for her family network, she stood out because, unlike so many of the families we talked to, she felt empowered even as she seemed to face daunting obstacles. An African American grandmother with custody of her two grandsons, ages fourteen and sixteen, Sonia took her responsibilities as their

guardian very seriously and was heavily involved in the boys' care and upbringing. The exact circumstances that led to Sonia's taking formal custody of her grandsons remained unclear, and we did not push her for more specifics than she was willing to volunteer; however, we did find out that the custody arrangement was the result of her daughter's use of drugs. Sonia, however, was unusual. She definitely saw herself as her grandsons' primary socializing agent and protector, and she fought to make sure they had access to various programs, including health care. Unlike most of the mothers we met, Sonia expressed a sense of competence in dealing with the welfare bureaucracy. She did not feel or express herself as though she were a helpless pawn in the system. Quite the contrary, she felt empowered to demand what she felt her grandsons deserved and felt competent to extract it from the systems with which she dealt.

One could hardly help but be impressed by Sonia's strength of character and her determination. She attributed her willingness and ability to engage the system to the influence of the politically active family in which she grew up. She told us that she also learned a great deal from the legal aid services in another city, which she had used to educate herself about the law. She had attended information sessions at legal aid services and also visited legislative offices where she could learn "what her rights were." Whether her attitude was the result of an innate positive temperament or her family's influence, Sonia stood out as unusual in her sense of competency to get what she needed from the bureaucracies she faced.

Like many of the mothers in our study, Sonia had been repeatedly denied welfare and associated services for her grandsons. However, as a woman who would not take "no" for an answer when she knew she was in the right, she vigorously set herself to the task of reversing the denials and had been successful in almost all cases. When we met her, the two boys were on SSI and Medicaid. A successful application for SSI almost always requires a lawyer because establishing eligibility is a complex process. Sonia's older grandson had both hearing and learning disabilities, and the younger boy had sickle-cell anemia and other associated health problems. Sonia explained to us that one of the boys was dropped from SSI for a period of time, but Sonia appealed the termination and attended a hearing where she served as her own advocate. With the support of the boy's doctor, she regained the SSI,

and her two grandsons have been continuously covered by SSI and Medicaid since then.

Sonia was creative and energetic in her efforts to keep the welfare, food stamps, and Medicaid she and her grandsons needed. She described with gusto her altercations with various welfare offices, occasionally drawing on a little poetic license. During one particularly contentious altercation with the welfare office, she wrote to her congressional representative, who intervened on Sonia's behalf. Sonia attributed the rapid and positive response by the welfare office to her willingness to take drastic action when necessary. It probably would not have occurred to many other women in her situation to bring political pressure to bear on the welfare bureaucracy. On another occasion, the state office told her that her documentation had been lost. Over their objections, she insisted on personally taking the paperwork to the comptroller's office in order to receive her check as soon as possible.

Sonia explained that "if you want your money you have to be persistent." During one episode of illness, her grandson was hospitalized off and on for over three months. The total bill was very large, but it was supposed to be paid by Medicaid. For some reason, however, the charges were denied. Again Sonia did not simply accept the judgment and worked with legal aid for two years to clear the debt. The basic principle that she lived by was that dealing successfully with the welfare office took a great deal of time, work, and knowledge. She believed that if she did not fight for her rights and those of her family, she would become a victim, and she was not willing to do so.

Sonia's efforts, or at least her account of them, reflected an effective use of the poverty programs on which poor families depend rather than movement toward real self-sufficiency. Ill herself, and living in a resource-poor neighborhood, Sonia had little access to jobs and little probability of ever obtaining the kind of job that would support her complex household and provide the full range of medical care all of its members needed. She, like most of the other families in the study, found herself embedded in an extended family network that placed additional demands on her time, energy, and material resources. On a daily basis, she shouldered burdens that required the complex support of multiple agencies. Again, the combination of limitations on Sonia's own opportunities, the resource-poor community in which she lived, and her responsibilities for children with multiple needs made

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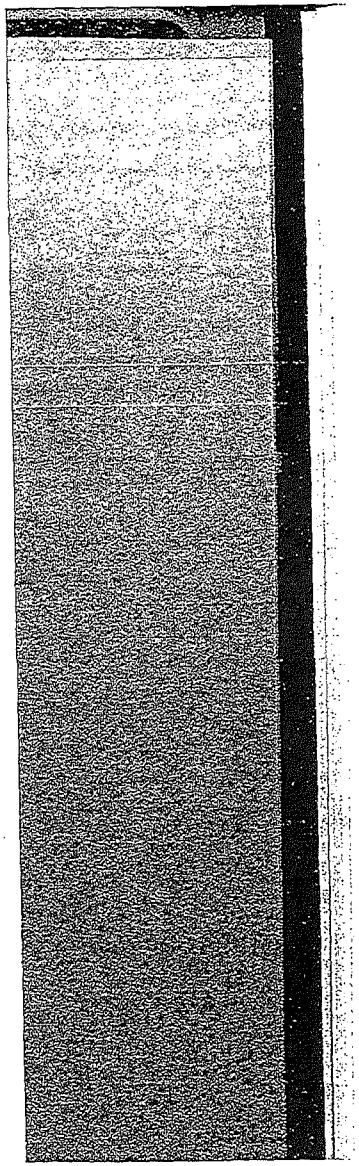

her dependent on welfare services and left little room for change in her overall economic status. As with Yvonne, Sonia rarely referred to race in her discussions of her own situation; however, she talked often about the welfare bureaucracies, the neighborhood resources or lack thereof, and the responsibilities she faced. Yet, in Sonia's case, it was clear that the situation in which the family found itself was clearly influenced by race.

Claudia

Few women in Sonia's situation had her knowledge, strength, and stamina. Unfortunately, for most poor mothers, the battle for benefits was often a losing one, and many simply went without the basic benefits for which they supposedly qualified on the basis of need or for which they did not qualify because even their rather meager earnings were too high for them to be eligible. At the other end of the spectrum were mothers like Claudia, who found it difficult either to locate or keep a job because of the demands of maintaining welfare support. Claudia, a young African American mother of two sons, ages four and five, was receiving Medicaid for herself and the two boys when she joined the study. She struggled continuously to keep the coverage. When we met her, she had only one year of TANF eligibility left. Among Claudia's struggles was an ongoing effort to get child support from the father of her older son. She had been receiving TANF since the older boy was born and had been trying unsuccessfully to get child support from his father since then. The office where she applied for assistance in getting child support was in the same building in which she applied and recertified her eligibility for TANF. She not only was required by the welfare system to seek child support from the father but also felt it was the father's responsibility and that he was shirking it. Unfortunately, like so many absent fathers who have never known their children, he evidently felt little obligation to his son. Keeping track of the father's whereabouts was difficult because he changed jobs as often as every week or two and it was hard for Claudia to locate him and to try to get him to pay. Claudia felt that obtaining the child support was all up to her because she got little help from the welfare system in arranging the child support that they required.

Because she wished to move to a nicer apartment, Claudia had applied for subsidized housing, and she had been on that waiting list

for at least three years. Once she finally received the voucher that she could use to pay the rent, she had a short period of time within which to find a landlord who would accept it. Although she might have been able to find an apartment, she had no savings, and the housing authority would not assist her with the initial deposit. Because she could not come up with the deposit, the window of opportunity closed before she was able to locate an apartment for which she could qualify with only the minimal deposit she could make. As a result, she again went to the end of the waiting list. It was hard to imagine that when she got to the head of the list again Claudia would be in any better situation to take advantage of it.

Claudia's failure to move the family to a nicer apartment was typical of her inability to use the welfare system to her advantage, and experiences like these were clearly demoralizing. Without child support and with the two young children, she had Medicaid, TANF, and food stamps, at least for the moment. However, because of the time limits imposed on TANF, she would lose cash assistance within a year, and she had no clear plan as to what she would do when that occurred. The future seemed bleak because, as was the case for most of the families we studied, finding a steady job with benefits was an unrealistic goal. When we were last in contact with Claudia, she was starting to look for work, but it was unclear whether she would be able to find appropriate child care, or whether she would receive assistance in paying for it. Even with a child care subsidy, she would have to locate the child care herself, and she was uncertain that she would be able to do so. Claudia also did not know how she would maintain health insurance for herself once she was off welfare. Claudia's situation was much more typical of our families than was Sonia's. She tried but was frequently unsuccessful in combining her ongoing search for a job, the requirements of the welfare system, and the other responsibilities of her life.

Of course, because we were relying on accounts of past events from our respondents themselves, we cannot confirm the accuracy of their information. All of the narratives contained inconsistencies that we were unable to reconcile and that, as we mentioned in Chapter 1, probably reflect the vagaries of human memory as well as the complexity of the situations that the families were facing rather than any desire to deceive. Whether Sonia was actually as effective in dealing with the

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welfare bureaucracy as she claimed to be we cannot verify. Nonetheless, the important point for our purposes is that Sonia felt that she was in control of her interactions with the welfare system, whereas Yvonne and Claudia did not. Perhaps even an unrealistic sense of control serves as a buttress against the demoralization that one might so easily fall into. Realistically, a poor family's control over important aspects of its life is limited. What Yvonne, Sonia, and Claudia shared in common, was that they were minority Americans. Each lived in an impoverished neighborhood, and each faced multiple heavy responsibilities with relatively few resources and few opportunities to increase their human capital and earning potential. All of these handicaps were clearly related to race and Hispanic ethnicity.

The Barrio

As these cases illustrate, one of the major mechanisms through which race and ethnicity affect life chances and health relates to the highly segregated nature of minority poor communities. Low-wage minority Americans live apart from the middle class in neighborhoods that many of our respondents characterized as having inferior schools and inadequate transportation or other public services. To many white Americans, the burden that our system of race-based social inequality imposes on individuals of color is unknown, and many clearly believe that serious inequalities have ceased to exist (McIntosh 1990). Unfortunately, serious inequalities and their negative consequences persist even today. The consequences of "ghettoization" and social exclusion are clearly detrimental for individuals and for the ghettoized group as a whole. Depressed individual earnings and limited asset accumulation translate directly into limited group assets and the deprivation-based interdependency that we noted among our study families. Residential segregation in impoverished neighborhoods with low levels of home ownership, little employment diversity, and few resources not only makes it difficult for families to save and to pass wealth on to future generations but also undermines the collective ability of a group to accumulate capital and increase their economic power (Goldscheider and Goldscheider 1991; Shapiro 2003).

Such ghettoization results from overt discrimination as well as the inability of poor families to afford more expensive housing in better

neighborhoods. It also reflects public housing policy and the placement and management of the public housing developments that dominate many poor neighborhoods. As our study revealed, even outside of the projects, subsidized housing is rarely located in more affluent neighborhoods. The literature documents, and our interviews corroborate, the resulting mismatch for residents of impoverished neighborhoods between residential location and economic opportunities (Glaeser, Hanuskek, and Quigley 2004; Kain and Quigley 1972). Residential isolation in a neighborhood that is a long distance from employment opportunities when one must rely on public transportation limits a worker's job options.

The fact of residential segregation, visible in all of the neighborhoods where we interviewed, relates directly to the issue of identity. Just as they found themselves in the waiting room rather than behind the desk at the Medicaid office, our families were relegated to neighborhoods and housing for the poor where those with more resources would not choose to live. In the same way that a counter or desk reifies the social distance between the welfare applicant and the representative of the system, poor neighborhoods, with their lack of amenities and natural beauty, reify the distance between the haves and the have-nots and play into the consciousness of the latter. In the course of our study, we were reminded time and again of how pervasive the symbols of powerlessness and dependency were in the lives of the families we studied and how they contributed to a cultural environment that undermined a sense of instrumental effectiveness. It is very difficult for those who do not live with such symbols of powerlessness and the experiences that accompany them to understand what the pervasive nature of poverty can do to the human spirit and to mental and physical health.

They Look Down on Us

As the case of the bank teller we mentioned in the previous chapter shows, one's group membership is an inescapable part of one's identity. Through hard work, the teller had been promoted to a higher position as a customer service representative and transferred to a branch where she was the only Hispanic. Although it is possible that her performance in the new position required improvement, the fact that her previous performance evaluations had been good enough to earn her

a promotion and the fact that her most recent evaluations were good, in addition to the nature of the criticisms she received from the supervisor at the new branch and especially the gratuitous reference to her ethnicity, make the critical evaluation suspect. The interviewer's opinion was that her command of English was very good. Once outside of their neighborhoods or their part of town, minority Americans are often made aware of their stranger status in very direct ways.

A few of our respondents did talk about their race or ethnicity as an issue in their access to public services, including medical coverage, but more of them mentioned the negative perceptions that they believed caseworkers and other program personnel had of them because of their poverty and their need to apply for welfare. Our respondents felt that, particularly in welfare offices, their social position and role as paupers became central and affected every aspect of the experience of applying for benefits as well as the likelihood that they would receive them. Our respondents only occasionally attributed difficulties in their lives to race or being Hispanic. In many domains outside of social program participation, however, it was clear to them that their poverty and lower social class were the root cause of their dilemmas. The fact that they were poor and powerless was no accident, however and in our interviews it was clear that their race and ethnicity colored how they believed they were seen and treated when they came into contact with any bureaucracy. Although some mothers reported cordial and even respectful relationships with caseworkers, many others believed that the system operated to debase and humiliate them. They interpreted the treatment they received as a continual reminder of their poverty status. One respondent explained that some caseworkers believe that clients lie. She felt that they judged everybody.

> They don't respect the people. For example, if you need an application, you have to stand in line, and they ask a lot of questions before they even give you the application, and if they think you don't need it, they don't give it to you. They ask questions like, "If you have income, if you work, how have you been making it with no income?"

One Latina mother, Graciela, who lived in Chicago, confirmed that a level of suspiciousness and a lack of trust existed between clients and caseworkers, a theme we heard repeated in all three cities, and this suspiciousness was often colored by racial and ethnic group differences. By the very nature of their role, caseworkers were seen as "gatekeepers"

in the application and recertification processes, as indeed they were. In the opinion of many of the respondents, if a caseworker believed that a family was either ineligible for a service or that the family really did not need the service based on the supporting material, or if the caseworker suspected that the family had other resources, he or she might well refuse to accept the application. Graciela, also like many other mothers, often felt demeaned by the nature of her interactions with welfare caseworkers because such interactions were completely asymmetrical and she was clearly powerless: "The caseworker doesn't care. She makes people wait for a long time." When Graciela attempted to apply for food stamps, her caseworker thought she made too much money to qualify or that she was at most eligible for only $45 in assistance. But as Graciela explained, even $45 "would help a lot...; it would be one month of food." So she persisted while the caseworker resisted. As she said, "The caseworker made it seem like why would you want just $45?" The caseworker never agreed to provide the forms necessary for her to apply for food stamps. Finally, when Graciela went to drop off a different application for medical coverage, she simply took one of the applications for food stamps and filled it in herself. By the time we met her, she no longer even wanted to talk to her caseworker. Whenever she could, she just mailed required documents to the welfare office and avoided interacting with caseworkers.

The issue of demeaning treatment by caseworkers and other bureaucrats came up often, and it was clear that the women felt their inferiority keenly in dealing with the system. The impacts of race and ethnicity are often subtle or indirect in that, as we have explained, they are confounded with differences in wealth, power, and organizational position. Even if one's caseworker or even if many of the caseworkers at the welfare office are of the same racial or ethnic group as oneself, the clients in the system are minority and the real power brokers and decision makers in the system are white. This racially and ethnically based gulf is palpable in its impact and colors the subjective experience of everyone involved. This is another pervasive phenomenon in the lives of the poor that is commented on only occasionally. Even when there are minority police officers on the beat in poor neighborhoods, the police department is seen as an agent of the white power structure.

The sources of humiliation and the reminder of one's inferior status pervade the welfare system and often seem to operate to undermine

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a person's attempts to gain self-respect. Given the fact that TANF stipends are low, particularly in Texas, most poor mothers are caught in a dilemma that arises from the fact that they have to find additional income in order to make ends meet. The cash assistance they receive is simply not enough, and most must find some additional source of money or in-kind support. (It is also clear that the income from a low-wage service-sector job is also insufficient to support a family.) However, any additional income must be reported to the welfare office and almost invariably results in the reduction of a family's TANF payment. Such a situation places poor women in the demeaning situation of having to lie about any additional income they bring in or accepting the almost impossible situation of living on welfare or a low-wage job. Again, the rules, which at times almost seem irrational, continually remind these women of their inferior and powerless positions.

One mother commented that the way they explain things at the office rather than what they tell you is "ugly." She said, "You feel low.... You say to yourself, ... if I take my time to go around all day and pick up cans, I've got to report this to these people? ... If I baby-sit somebody's kid and make ten dollars, they say you have to report that." In the interactions with bureaucrats that she described, this mother, like many of the women we interviewed, was forced, on the one hand, to emphasize her own poverty and powerlessness in order to qualify for the help she could not do without and, on the other, to dissemble about the hard work and cleverness she put into strategies to make things work for her family.

Although most respondents talked in terms of how their poverty and their low levels of education were the cause of the humiliation they endured, some of the mothers in our study were more specific in talking about the impact of race on their experiences with the welfare system. In response to the question "Do some people get treated better or worse than others?" one mother answered as follows:

> Yes. People that have a lighter complexion, white people, they get better treated. We as Hispanics get treated automatically badly or they talk to us rudely because they think we don't know what we're doing; we're just taking advantage and we don't want to further ourselves. So they automatically think badly and talk badly to us. They think they can walk all over us. That's why when I go I have to speak up and let them know that [even though] I'm Hispanic and I'm on welfare, I'm trying to better myself. That doesn't give them the right ... to walk all over me. Because I know what they're telling me and I know what I have to do. They think we're dumb and we don't know, but we do know. Then they won't be able to walk all over me. They know where they stand with me.

Such overt ethnic attributions were rare, but our respondents were clearly aware of how the racial concentration of the poor neighborhoods in which they lived, their group identity, and particularly the poverty that peruaded the neighborhoods in which they lived limited their opportunities and their ability to obtain education, increase their earnings, and offer a better life to their children.

Conflict and Barriers to Coalition Building

One destructive aspect of race relations in the United States is the degree to which different disadvantaged groups often find themselves in conflict with other disadvantaged groups. In San Antonio, we observed a great deal of conflict and ill will between African Americans and Mexicans as they vied for housing and other limited public resources. Sheila was one of the few non-Hispanic white women in our study. She was the mother of two children, ages three and four. Although she was not Hispanic, her husband, who was the father of her children, was Hispanic, and Sheila had lived in Hispanic neighborhoods for much of her adult life and had inculcated much of that identity, including that of being poor. Sheila's husband abused her and was in jail at the time of our interviews. Even though she was not Hispanic, the fact that she was married to a Hispanic man and was living among African Americans at the time colored her subjective experiences, much as it did those of Hispanic women. Among other topics, she told us about both her caseworker and the demographic realities of public housing as she saw them.

"My caseworker here at [the development], God I swear I hate her, she is deterring me.... I put the transfer in [to move to a different housing development] but she says until your rent is paid, until this is done and this is done, we're not going to transfer you." Sheila told us how threatened she felt knowing that her husband knew where she lived and could find her when he is released from jail. She believed

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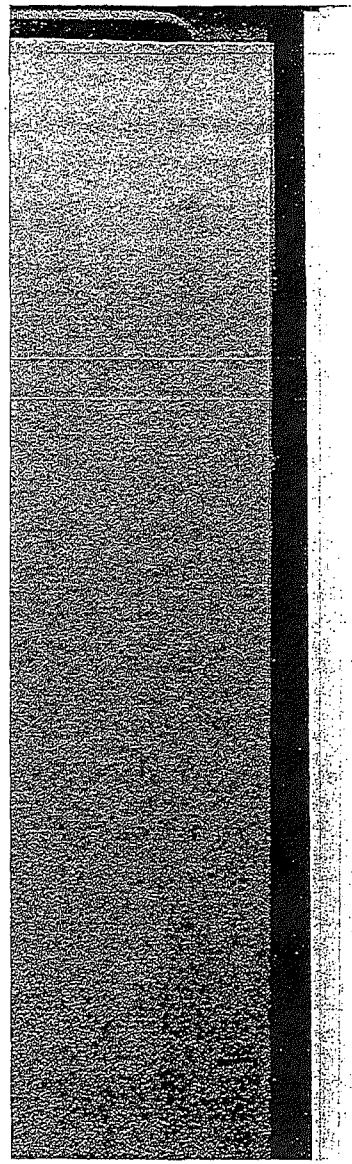

Unfortunately, the earlier the disease manifests itself, the longer it has to do its damage. Teresa's sister also had diabetes, and given the probable genetic predisposition among Mexican-origin individuals, the disease often affects several family members. The poverty in which Teresa lived undoubtedly contributed significantly to the onset of the disease and the course it took over the years. Diabetes is a chronic disease that requires constant vigilance in order to avoid extremely serious secondary problems, including heart disease, kidney failure, blindness, and peripheral nerve and blood vessel damage that can require the amputation of limbs. With proper management, which includes constant monitoring of one's blood sugar, close dietary control, and regular exercise, the ravages of the disease might be avoided. Without constant vigilance, they cannot.

The disease was the source of constant worry and many problems in Teresa's life. Despite the seriousness of her condition, however, she was unable to obtain all of the medical care she needed to deal with the disease and its consequences. Teresa's history of diabetes was long and complicated. It was often hard to tell whether she had ever received clear instructions concerning appropriate medication use or the appropriate diabetic diet from any of the physicians she had seen. She may, of course, simply have been noncompliant and not been following their advice. There was no way for us to know. As we got to know the family well, however, we realized that Teresa was not following the standard diabetic diet, which is low in sugars, salt, and fats. The family's meals, which Teresa shared, consisted of what many poor people eat, including prepared foods that are high in the components she should have been avoiding. We also suspected that she was not taking the correct dosage of her medication because she complained of numbness and dizziness. What we learned from our interactions with families in the study is that people on very limited budgets often take lower doses of prescription medications than they are prescribed in order to make the medicines last longer. Needless to say, such a practice seriously undermines the effectiveness of the treatment.

Despite the serious long-term consequences of poorly managed diabetes, Teresa was not able to get appointments to see a physician monthly as she had been advised, and her condition deteriorated during the course of the study. In our first interview in July 1999, Teresa reported that the doctor had recommended swimming as part of her

treatment because there was a swimming pool at the development in which the family lived. Although she told us that she had been able to go to the pool a couple of times, taking care of her baby prevented her from swimming regularly.

At times Teresa seemed not to understand her medical condition or how it should be treated. Like many individuals with chronic diseases, she had tried many home remedies, but none had worked. Once she was diagnosed, which must have been well into the disease process, Teresa began taking pills to control her blood sugar. Within a year, the disease had worsened and she needed insulin injections. During a six-month follow-up interview in February 2002, she told us that she no longer took insulin because it made her feel worse. Instead, when she felt that her blood sugar was low, she would eat a piece of candy or drink a glass of orange juice. At our twelve-month follow-up interview with her, Teresa told us that she was again taking insulin.

At the time we recruited her into the study, Teresa was still receiving the Medicaid coverage for which she had qualified while she was pregnant with her infant son, and she was getting some financial assistance from the father of one of her daughters. She did not receive any assistance from her son's father and no longer had any contact with him because, as she told us without offering any specifics, he had molested one of the girls. After her last pregnancy, Teresa had experienced numbness in her legs, and by July had difficulty walking, but at the time she did not have a car. In order to get to her doctor's appointments or to appointments at the welfare office, she had to walk several blocks to the nearest bus stop.

Teresa's health problems were clearly compounded by those of her children. Despite the obvious urgency of her own medical problems, like so many other parents she focused her time and resources on getting them care first. In addition to forcing Teresa to ignore or postpone her own care, getting care for her children placed real physical demands on her body that exacerbated her condition and drained her energy. Even with her strong desire to do right by everyone in the family, there was only so much she could do. Because of the difficulties she had with transportation and the difficulty she had walking, she had a hard time keeping medical appointments with her own or her children's regular doctor. Instead, she would often take the children to one of the local clinics to which she could more easily travel by bus.

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A year after our first interview, and as her condition deteriorated, Teresa developed glaucoma and black spots appeared in her visual field. Despite her vision problems and the clear financial sacrifice, she bought a car in order to get to and from the jobs that she could find. Her legs continued to bother her, and her fingers, hands, and feet began to ache. By this point she was taking three different oral medications in addition to insulin, although we were never certain what those were. She also had been told that her diabetes had affected her organs, but she offered no details. Soon after that she reported that her kidneys were severely damaged. As her health continued to deteriorate, her medical care and medication use remained episodic.

The family's life was clearly consumed by health problems and the need to find care, and Teresa often had a hard time understanding or complying with treatment recommendations. Both of her daughters had been diagnosed with learning disabilities and had been placed in special education classes. The younger daughter also had attention deficit hyperactivity disorder (ADHD) and had been prescribed Ritalin. As with her own diabetes, Teresa seemed uncertain as to how to deal with her daughter's problems. The Ritalin prescription called for the drug to be administered three times a day, but according to Teresa it caused the girl to lose her appetite and become sluggish. In order to reduce those side effects, Teresa decided to have the girl take the Ritalin only while at school so that she would not "throw fits" and disrupt the class. She seemed either unaware of the need to comply with the specific prescription requirements or chose not to do so for reasons that were not really clear. While we were in contact with them, the family's problems only got worse. By May 2000, the boy was showing signs of developmental delay; he could crawl but not stand by himself. In addition, he had developed asthma.

Teresa had a tenth-grade education and had been struggling to complete her GED before her son was born. Unfortunately, her poor health interfered with her education as well as her ability to find work, and she was unable to finish the course. Despite not having a degree, she found employment as a nursing assistant and was able to leave welfare for a while. As was the case for many other mothers, however, the job was only temporary, and Teresa stopped working during her pregnancy because she was increasingly ill with her diabetes and bronchitis. Although the nursing assistant position paid slightly above minimum

wage and was full-time, it provided no benefits for her or her children, and while she was pregnant she became eligible for and received Medicaid and TANF.

For adults with serious disabilities, Social Security insurance provides more reliable health care coverage and qualifies a family for TANF. Teresa began the process of applying for Social Security insurance support for herself in mid-1999. After her younger daughter's hyperactivity was diagnosed, she also applied for supplemental security income (SSI) for the girl. These applications were not immediately successful and, as is the case with most SSI applications, Teresa had to make several administrative appearances and spend a great deal of time and effort finding and presenting documentation before the two cases were approved. Meanwhile, because of the TANF work requirements, Teresa was continually reminded that she was required to look for work for several hours per week, a requirement that she could not always meet because of her own health problems, her children's health problems, and the administrative struggles required to deal with them. In 1999, while she was pregnant, she was threatened with being sanctioned for not working, but she successfully fought penalties by proving that she was five months pregnant. She knew that although she would have a grace period after the birth, she would again be required to look for work.

Meanwhile, in early December 1999, well before the disability cases were settled, Teresa and her children moved into a shelter for awhile because she did not have money for rent. During this period when the family was homeless, her welfare benefits were cut even further because her oldest child missed a week of school. Through it all, Teresa continued to try to get medical care for her illness and to qualify for government support, but out of desperation she began to look for work even though she anticipated that once she was employed she would lose all assistance, including her medical coverage.

Because she had received training as a nurse assistant, Teresa felt certain that she could find employment, but she had serious anxieties about the job's physical demands, which included lifting patients, and initially she sought other work. She found a job cleaning up after games at the local sports arena, but she quit that job after only three weeks. That job paid only $5.50 an hour and required that she work at night. Teresa could not find anyone to take care of her children while she

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worked the evening shift. In addition, the job was physically challenging, especially given her health problems. The job finally ended with her son's sudden illness and hospitalization with pneumonia. Even after her son recovered, Teresa decided not to return to the night job.

By February 2000, Teresa's daughter had qualified for SSI and she became eligible for a number of new programs and medications. Meanwhile, Teresa's application for Social Security insurance continued to be denied. In December 2000, she told us that her vision was deteriorating because of her glaucoma and cataracts. However, despite her deteriorating health, her physician would not certify her disability status because, according to her, he viewed her problems as arising from weight gain and he thought that she should be able to control the symptoms by losing weight. By now Teresa had a car so, although driving with impaired sight was a risk, she drove to her monthly checkups. Her new job as a nursing assistant, however, created a different problem. Because the job did not provide sick leave, she missed many of the appointments even though she had transportation because she could not afford to take time off from work.

By February 2002, Teresa had to quit working again. She was having trouble standing or walking because her legs would become numb and collapse under her. She told us that a pinched nerve in her back had caused the problem. Because of the pain, she remained seated much of the day and used a cane to walk. The nursing care company could not keep her on under these circumstances, and the family again became dependent on welfare.

Finally, following the numerous hearings that are typical of Social Security insurance applications, Teresa was approved in August 2002. She told us that she believed that she had been approved only because she had been sent to specialists recommended by the caseworkers. As a result of receiving these funds, Teresa made immediate changes in the treatment of her diabetes. She told us at our twelve-month follow-up interview that she had begun to receive treatment at a new clinic in her neighborhood and even attended "diabetes classes" to learn about proper diet and exercise for diabetics. The clinic also offered exercise classes, but because the location at which they were offered was too far away, Teresa exercised by walking around the neighborhood instead.

By fall 2002, Teresa was trying to find out how she could make her house wheelchair-accessible because she believed that having a

wheelchair would make her house chores and taking care of her youngest child easier. Although she continued to drive, she was increasingly dependent on her eldest daughter, who had a learner's permit. At the time of our last contact with Teresa and her family, they were clearly better off than when we met them, largely because of the Social Security insurance and supplemental security income that Teresa and her daughter were receiving. Nonetheless, it was clear that their struggles to maintain health care coverage for other members of the family would continue and that Teresa's health problems would continue to undermine her efforts to get ahead. Although she was a relatively young woman, Teresa's body had been ravaged by her diabetes and its complications. Like so many other parents, she had neglected her own health in her struggle to get care for her children and maintain a home for them. Teresa's case clearly illustrates the fact that poor families face greater threats to their health and are more likely to suffer from the long-term consequences of illness that might be avoided by early and adequate medical care. Without coverage, that care is often unavailable, and poor health undermines its victims' educational ambitions, their attempts to stay employed, and their effectiveness as parents.

Yvonne's Health Problems

Yvonne, the Mexican American mother of five whom we met in the last chapter, offered another poignant example of a low-income adult's dilemma when it comes to her own health care. In the last chapter, we recounted the many problems that Yvonne faced and showed how her poverty and her minority-group identity contributed to the difficulties she had in dealing with them, which in turn increased her depression and demoralization. As was so often clear in our study, the health risks associated with poverty manifest themselves both physically and emotionally, and as with Yvonne we encountered much depression and more serious mental illness. Yvonne's demoralization was fueled in large part by poor health and the difficulties in getting care for herself and everyone else in the family. She suffered from the long-term effects of a childhood spinal injury for which she took medication in order to control the pain. Getting the medication on a regular basis was a problem because of her lack of insurance. Adults like Yvonne, who do not qualify for Social Security insurance, must rely on Medicaid when they can get it and charity when they cannot. A few nongovernmental